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Cover picture: Fabio, from Switzerland, with his sisters Tanja and Elena
Welcome to the fourth issue of volume 4 of *Down Syndrome News and Update*. The Down Syndrome Educational Trust works with the European Down Syndrome Association (EDSA) and with Down Syndrome International (DSI) to draw together the content for this publication. Our aim is to share practical, evidence-based information to contribute to the care, education and ultimately the quality of life of children and adults with Down syndrome and their families.

**International perspectives**

In this issue, we have contributions from an exceptional person with Down syndrome in Japan and on cultural issues from Indonesia, health care from Canada, a Disability Discrimination summer school in Ireland, and new resources for personal and sexual education from Australia plus news from EDSA and DSI. The next meeting of the European Down Syndrome Association (EDSA) is in San Marino, Italy from 27th-28th October 2005 and the next major DSI event is the 9th World Congress in Vancouver August 2006.

**Features**

A theme of this issue is the variability of the outcomes for children with Down syndrome and the factors that may affect this. The introduction opposite discusses this issue further, stressing a need to focus on the children and adults with more severe disabilities and their families. However, we also include an article from an exceptionally able young woman from Japan – and this range of outcomes does reflect the real-life picture for individuals with Down syndrome. The diagnosis of Down syndrome does not allow us to predict the future for any child in the first few years of life.

**Autism and Down syndrome**

This article is an overview of what we currently know about autism and Down syndrome, drawing attention to the risk of over diagnosis if too much emphasis is given to repetitive and stereotyped behaviours. This is not to minimise the needs of children who do have autism and we offer some guidelines for intervention strategies – but we need more research and more evaluation of teaching approaches. As a start, the children should access autism services in their communities.

**Expert health care provision**

The next article from Calgary, Canada describes the way a specialist, multi-disciplinary health care service benefits children with Down syndrome, their families and their primary care providers across a region. The case example highlights the benefits for a child with more complex needs than the typical child – but many other children may have some but not all of these health issues and they are often missed by physicians and wrongly seen as just ‘part of Down syndrome’. The benefit of specialist services is clear across North America but there are not many examples outside that continent – a notable exception being the service in Barcelona provided by the Fundacio Catalana Sindrome de Down, which also hosts a regular international conference on genetics and health issues. The abstracts from their meeting in March this year will be published in the next issue of *Down Syndrome Research and Practice*. Most of the specialist clinics have close support from their local parent associations who have lobbied for their creation and often continue to provide additional funds for the service, as in the Calgary case.

**Exceptional achievement**

I had the pleasure of meeting Aya in New Zealand at the conference she mentions in her article about her life. Her achievements reflect her hard work and determination and that of her parents. They did not lower their expectations for her – if they had done so she would not have achieved as she has. This is a difficult path for families in the early days – and for professionals – to see each child as an individual and not be too influenced by the diagnosis. We do still need to fight to raise expectations – many young people with Down syndrome do not reach the level of skills and independence that is possible for them – while taking good care of the more severely affected children and families.

**Screening and early counselling**

Aya raises the issue of screening and termination and how we need to fight negative attitudes and this point is also made by Kirsty’s dad, a paediatrician in the UK. He points out that still too many doctors are ignorant of the achievements of the majority of children with Down syndrome, and the way in which they enrich the lives of their families. A letter from Rhiannon’s parents highlights this – even though she has significant delays. There are real dilemmas here – we need to ensure all parents are able to make well-informed choices and hope that they will then feel able to proceed with the pregnancy. Sometimes couples already have a child with Down syndrome whom they love dearly but they do not feel they could cope with a second affected child. Some difficult issues and no black and white solutions here – readers reactions and comments please.

**New publications**

We review an excellent resource from South Australia on *Friendships, Sexuality and Personal Safety* – this will be welcomed across the world as an excellent and flexible resource. We also review research on the specific profile and early intervention – can we change the profile if we intervene early and reduce the delays in language and cognitive progress compared to social progress? A very important question – join us at our September Conference for the latest views on this and many other cutting edge issues – Early Bird Registration has been extended to 8th July so book now. The full programme is on our website – see link from home page.

**Keep writing**

Thank-you to all our contributors – please keep your articles, letters and news coming.

Sue Buckley OBE is Director of Research at the Down Syndrome Educational Trust, Portsmouth, UK, and Emeritus Professor of Developmental Disability at Department of Psychology in the University of Portsmouth, Hampshire, UK.
Children with additional needs

A major theme running through articles in this issue is the care of children with Down syndrome who have additional needs, arising from complex health problems or from having another disabling condition as well as Down syndrome

Helping the majority

For many years, everyone working to improve the quality of life for individuals with Down syndrome has worked at understanding the needs of the majority. This has led to many important steps forward in understanding how development is affected by having Down syndrome, especially in the areas of speech, language and cognitive development. The awareness of the ‘specific profiles’ of development and how they can lead to more effective early intervention and education programmes was a theme in the last issue of this publication. For many years, there has also been a need to raise awareness of the potential of individuals with Down syndrome and to raise the expectations of parents and teachers from the low expectations of the past. As we have made significant progress in understanding and advocating for the needs of people with Down syndrome, so we have also become more aware of the wide variation in needs and, in particular, of the needs of those with substantially greater levels of difficulties and disabilities than the majority.

Neglecting the minority

Over recent years, when organisations have been focusing on educating the public and professionals to have higher expectations and improve educational and life opportunities for individuals with Down syndrome, some parents have felt that they and their children, were not being understood or represented by these campaign leaders. The Down Syndrome Educational Trust, like other organisations, has received and published letters reflecting this from parents who feel sad and demoralised when they read of the achievements of children with Down syndrome whose progress is way ahead of that of their own child. It is time that we focused attention on the needs of these children and their families, and worked to describe how their needs differ from the majority so that we can address them better.

Complex health needs

There are several groups of children who might be described as atypical – not like the majority of children with Down syndrome. One group are children with complex health and medical needs such as the child described in the article by Donna Heerensperger, from Calgary in Canada. Sometimes families and children have to continue to deal with ongoing health needs that do not significantly affect developmental progress, but sometimes health complications lead to additional brain damage and seriously affect development.

Autism

Another group are the children with autistic spectrum difficulties in addition to Down syndrome. The core difficulty in autism is in relating socially to others. Most readers will be familiar with how social and socially engaged most babies with Down syndrome are – the way they make eye-contact, smile, enjoy babble games and go on to communicate in sign and speech. Most children with Down syndrome are keen to play with others, engage with family members, join clubs and socialise. In theory, a child with Down syndrome can also be affected by any other possible disabling condition or health problem and, on this basis, we would expect a number to be unfortunate and have autism and Down syndrome. We would predict that the number to have autism would be similar to the rates of autism seen in the larger population of children with learning disabilities.

Less than expected

In fact, the number of children with Down syndrome and autism is significantly less than would predict (10 in 100 at most rather than 17 in 100). It could be argued that children with Down syndrome do have real strengths in social understanding and social engagement, which actually reduce the risk that they develop autistic difficulties. While this may be reassuring to the majority of parents of young children reading this, it does not lessen the pain and additional difficulties faced by families with children with Down syndrome and autism. We need to understand the needs of these children in more depth and the first article in this issue reviews what we know at present – drawing on research into autism in the whole childhood population as well as research into Down syndrome and autism.

Studies indicate that there are probably two groups of children with Down syndrome and autistic spectrum disorder and that there is an overlap with the children with complex health needs and additional brain damage. One autistic group are the children with the most complex and profound levels of learning disability and the other is children with more mild/moderate levels of learning disability – therefore speech, language and cognitive skills similar to most children with Down syndrome but a specific autistic difficulty as well. These issues are explained more fully in the article.

ADHD and behaviour

Other children who may be atypical are this with ADHD (attention deficit hyperactivity disorder) and those with unusually severe behavioural difficulties. We will turn our attention to these in future issues. Meanwhile, we would welcome any family letters and photographs if you would like to tell us about your son or daughter with additional needs. At the Trust we are planning some research on this and we will start with collecting information from families. Keep an eye on our website for more news on this.

Editor
Autism and Down syndrome

Sue Buckley
The Down Syndrome Educational Trust, Portsmouth, UK

How many children with Down syndrome also have autism and how do we meet their needs?

Introduction
In recent years, there has been an increase in the number of children with Down syndrome who are being diagnosed as having autism or autistic spectrum disorder. These children are then referred to as having a ‘dual diagnosis’ i.e. two co-existing conditions. However, it is not easy to diagnose autism in children who already have a learning disability and there is not clear agreement on the numbers of children with Down syndrome who do have autism or features of autism. Some authors [1] argue that the diagnosis is missed because children with Down syndrome are thought to be sociable and, if this is true, some children and their families could be missing out on treatment and services they might benefit from. Others, including myself, are concerned that there may be a tendency to over-diagnose autism in children with Down syndrome. This could lead to changed and lowered expectations for children’s progress as well as distress for families.

I recently put out a call to families for photographs and developmental histories if their children had a diagnosis of Down syndrome and autism, and many parents responded. The histories of Conner and Daniel, (see boxes) give us some idea of the needs of this group of children. With colleagues, I am planning further research and we will be collecting information from as many families as possible using a survey in the initial stages, as we need to know much more about the profiles of these children if we are to improve the accuracy of diagnosis and provide as much effective help as we can as early as possible.

Difficulties with diagnosis
There is no objective test for autism such as a blood test or a brain scan at the present time. The diagnosis is made on the basis of having a particular pattern of development and behaviours, described below. However, many of the individual behaviours are not indicative of autism on their own. Many of these behaviours are seen in typically developing children at early stages in their development and may be seen for longer in children who are delayed in their progress. Children with delays in communication, children with hearing and vision impairments, children with brain damage and children with severe learning difficulties are all more likely to show behaviours that are on the autistic symptom list. This means that there is plenty of room for different opinions and for mistakes in diagnosis.

What is autism?
Autism is essentially a social impairment, affecting children’s ability to communicate with and to socialise with other children and adults. There are three main clusters of symptoms recognised as important for diagnosis:-
1. Social impairments
2. Communication impairments
3. Repetitive stereotyped behaviours

A diagnosis of autism requires significant impairment in all three areas (see ICD-10 criteria in box on page 116) but a child who shows some but not all the difficulties may be described as having autistic spectrum disorder (ASD) not full autism. In the USA, autistic spectrum disorder is described as pervasive developmental disorder (PDD). The pattern...
Conner’s Story

Conner is 5½ years old. He has red hair and green eyes, along with Down syndrome, autism, Celiac Disease and asthma. He’s very mischievous, cunning and resourceful when he wants something. Conner just finished his first year of kindergarten. He was in a fully inclusive preschool program, taught by special education teachers, and supported by occupational, physical and speech therapy before he started kindergarten. We also had early intervention services from the time he was 4 months old until he was 3 years old.

This year, Conner has learned all of his ABC’s and is able to recognize numerous sight words. We aren’t sure how many he knows, as he does not talk, but uses signs, gestures and an augmentative communication device to communicate with us. He can also match lower case letters with upper case letters. He has been learning to count to 20 and match the number to the corresponding correct number of objects. He knows shapes and colors, and is able to recognize some objects by their descriptors or location (such as small, big, yellow, next to). These concepts are still a bit difficult and his mastery at this point is hard to pinpoint. He has an incredible memory (not usually associated with Down syndrome), but only for those things that are of intense interest to him.

At home, Conner helps with some household chores, such as sorting laundry by color and putting it in the washing machine or dryer, putting away silverware, making his bed, putting clothes in the hamper, picking up his toys, etc. He even has begun to assist with caring for his 2-month-old baby sister (with close parental supervision of course). He has taught himself how work the VCR, turn on the computer, open and close the games on the computer that he likes – we did not show nor teach him any of those things. He is able to follow 2-3 step commands, especially if they are familiar, such as “put the comb in the drawer and your clothes in the hamper” after his bath.

As Conner’s mother, I’ve known he had a dual diagnosis of Down syndrome and autism since he was 1½ - 2 years old. We just got an official diagnosis of autism last week however. Our family doctor is very uneducated and inexperienced with autism so he was not a good resource for us, though he is supportive. Conner’s therapists from early intervention program (birth to 3 years) did not believe he had autism – they said he was ‘too social’ because he would give them hugs and us. His teacher and therapists (occupational, physical, and speech) in his fully inclusive preschool class also did not believe he had autism because they did not see in their highly structured environment the repetitive behaviors we encountered at home such as spinning himself or objects, dangling objects, looking at the TV up close and from all angles, watching the music come out of speakers, avoiding other people (esp. children), sensory defensiveness (auditory and tactile), and numerous other things. They did observe he did not particularly like his classmates nor interact with them, but they attributed that to immaturity or mental retardation associated with Down syndrome. In fact, when I requested an autism assessment at the end of the first year of preschool, the principal called me in for a meeting to ask why I wanted the assessment. After the meeting, one of the diagnosticians from the school district came to observe Conner and review his records. She said she did not see any signs of autism, and really did not think a full evaluation would be beneficial. The principal did listen to our concerns, and they sent an in-home trainer to us for 5 visits to assist us with some of the issues at home.

By the end of his second year in preschool however, his teacher did agree that he probably had autism, as some of the behaviors we saw were more pronounced. Since he was very ‘a-social’, we (parents, teacher and speech therapist) decided that he should go to kindergarten where he would go to school for a whole day, rather than a half-day. Because of his birth date, he could have stayed in preschool one more year. We thought it would be more beneficial to him to have a whole day with more structure than we could provide at home rather than a half-day that preschool provided.

This year, we were scheduled to have another Full Individual Evaluation (FIE) for Conner. Every 3 years one must be completed if a student is receiving special education services. We again requested the autism assessment and the school agreed. The assessment was conducted last week, and the doctor, therapists, and diagnostician (the same one who said she did not see any signs 2 years ago) all agreed that Conner was in the unique minority of having both Down syndrome and autism.

It has been a relief to have that actually ‘officially’ diagnosed. It now helps us to be able to explain to extended family members why he has some of the quirky behaviors, and they seem to understand better. The diagnosis does not change who Conner is. Nor is it going to change much in his Individualized Education Plan next year because his father and I have already advocated for the things he needs to be successful in school, in a regular kindergarten class. We have agreed, that because of his age (he won’t be 6 until after school starts next year), that repeating kindergarten is a good idea, though academically he could be successful if he went on to 1st grade. It is also comforting as a parent to be validated and vindicated to some degree – to know that the paid professionals now see what we’ve known for years, and that we are not crazy. I feel like I can take a deep sigh of relief because his teachers and I will ‘officially’ be on the same page when discussing what he needs to be successful in school by addressing some of his unique needs.

Kelly Theriault

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http://www.down-syndrome.info/library/periodicals/dsnu/04/03/
ICD-10 criteria for a diagnosis of autism

A. Abnormal or impaired development is evident before the age of 3 years in at least one of the following areas:
(1) receptive or expressive language as used in social communication
(2) development of selective social attachments or of reciprocal social interaction
(3) functional or symbolic play and
B. A total of at least six symptoms from (1), (2) and (3) must be present, with at least two from (1) and at least one from each of (2) and (3):
(1) Qualitative abnormalities in reciprocal social interaction are manifest in at least two of the following areas.
(a) failure adequately to use eye-to-eye gaze, facial expression, body posture, and gesture to regulate social interaction
(b) failure to develop (in a manner appropriate with mental age, and despite ample opportunities) peer relationships that involve mutual interests, activities and emotions
(c) lack of socio-emotional reciprocity as shown by an impaired or deviant response to other people's emotions; or lack of modulation of behaviour according to social context; or a weak integration of social, emotional, and communicative behaviours
(d) lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g. lack of showing, bringing or pointing out to other people objects of interest to the individual).

(2) Qualitative abnormalities in communication are manifest in at least one of the following areas:
(a) delay in, or total lack of, development of spoken language that is not accompanied by an attempt to compensate using gesture or mime as an alternative mode of communication (often preceded by a lack of communicative babbling)
(b) relative failure to initiate or sustain conversational interchange (at whatever level of language skills is present) in which there is reciprocal responsiveness to the communications of the other person
(c) stereotyped and repetitive use of language or idiosyncratic use of words or phrases
(d) lack of varied spontaneous make-believe or (when young) social initiative play

(3) Restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities are manifested in at least one of the following areas:
(a) an encompassing preoccupation with one or more stereotyped patterns of interest that are abnormal in their intensity and circumscribed in nature though not in content or focus
(b) apparently compulsive adherence to specific, non-functional routines or rituals
(c) stereotyped and repetitive motor manoeuvres that involve either hand or finger flapping or twisting, or complex whole body movements
(d) preoccupations with part-objects or non-functional elements of play materials (such as their odour, the feel of their surface, or the noise or vibration they generate).

For ‘atypical’ autism the impairment can be identified after 3 years of age

and severity of symptoms can vary from child to child.

How is autism diagnosed?

The diagnosis of autism or autistic spectrum disorder is usually made by a psychiatrist. The psychiatrist will use the diagnostic criteria set down in one of the two major diagnostic guides, the ICD 10 (International Classification of Diseases,(2) World Health Organisation) or the DSM IV in use in the USA. The psychiatrist may use clinical experience to make a diagnosis based on the ICD 10 or DSM IV criteria but increasingly one of two standard diagnostic tests will also be used. These are the Autism Diagnostic Observation Schedule (ADOS) and the Autism Diagnostic Interview (ADI). The use of these measures, for which specialised training is required, improves the reliability of diagnosis. However, a child may need to be seen in familiar environments at home and in nursery or school – not just in the clinic – to obtain a full picture of their behaviours and difficulties (as Conner’s story indicates).

At what age can autism be diagnosed?

There is now general agreement that an experienced professional can reliably diagnose autism by 3 years of age in the general child population. There is also evidence that some children may be identified earlier on screening tools,(3) relying on early indicators such as differences in eye-contact, joint attention, pointing, imitation and play behaviours.

What causes autism?

While autism can be recognised and described, the causes of autism are not understood and for the past 20 years there has been an enormous amount of research into the condition. Researchers are investigating the genetics, the brain development and the biology of autism and some progress has been made.(4) The suggested link with MMR jabs has been discredited(5) but there have been no major breakthroughs. There is evidence of a genetic pattern and a tendency for autistic profiles and/or communication difficulties to run in families.

Psychologists have been investigating the differences in social and emotional development, in behaviour and in cognitive development. Some of this work has led to awareness of some early social behaviours which may be important indicators of autism but not to any breakthrough in understanding causes. Readers may be interested to know that in many of these research projects, the performance of children with Down syndrome and children with autism, matched for IQ and age, has been compared. The majority of children with Down syndrome do not show the deficits in social and emotional understanding that are shown by the autistic children.
How common is autism?

There are quite widely varying estimates in the UK and USA because there are no objective measures of autistic spectrum disorders. In the 1970s the estimates of the incidence of autism were 4-5 autistic children per 10,000 children. Currently estimates vary from 18.7 per 10,000 to 91 per 10,000. Since the 1970s, there has been an increased recognition of ‘milder’ social impairments such as Asperger syndrome, which are now part of the autistic spectrum disorders and this accounts for some increases but not all. There does seem to be evidence for a genuine increase in the numbers of children now having autism and autistic spectrum disorders. Of all individuals with a diagnosis of autistic spectrum disorder, some 50% have learning disabilities.

How does learning disability affect autism?

Surveys show that the incidence of autism increases as the severity of learning disability increases. In a recently published article looking at autistic spectrum disorders ( pervasive developmental disorder) in the total population of individuals with learning disabilities in an area of The Netherlands they report the following figures. In a total group of 1436 children between 4 and 18 years, 9.3% of those with mild learning disabilities were diagnosed as having autistic spectrum disorder, 16.8% of those with moderate learning disabilities and some 43.4% of those with severe or profound learning disabilities. This study gives an overall incidence of 16.7% for the total group of children with learning disabilities (IQ of 70 and below) or 26.1% (IQ of 50 and below). Similar figures have been reported from studies in Sweden and in the UK. These studies use IQ measures to group children by degree of learning disability as shown in the side box.

Most children with Down syndrome are within the range of mild to moderate learning disability – with about 10% in the severe/profound range. We might predict that the expected rates for autism and Down syndrome would be the same as those for the learning disabled population as a whole given above, but we will see below that they are probably significantly lower.

What do we know about Down syndrome and autism?

How common is it?

Over the past 25 years, some dozen papers have reported cases of children and adults with Down syndrome and autism. There have also been some surveys in the UK[1] and Sweden[2] which suggest that about 5-7% of children with Down syndrome have autistic spectrum disorders. A recent study of a sample of young children in the USA found 2 children in a group of 20, giving a 10% incidence.[3] These all suggest that the rate is considerably lower than the 16.7% that would be expected for children with IQs across the mild/moderate/severe range. In fact, it could be argued that children with Down syndrome have some inbuilt social strengths that reduce the likelihood of having autism despite their delayed language and intellectual development.

A link with level of disability

The published case reports do not always include information on degree of learning disability but in those that have this information, a substantial number of the individuals described with Down syndrome and autism have severe to profound levels of disability. In 19 cases where the information is given, 12 (63%) have severe to profound levels of disability, 6 (32%) have moderate learning disability and 1 (5%) has a mild learning disability. In other words, most young people with this dual diagnosis were in the most delayed and cognitively impaired group of children with Down syndrome.

Family and health factors

Some studies have identified that a history of autism spectrum disorder was present in the families of some of the children with Down syndrome who were diagnosed as autistic.[4,5] Like other children, they are being affected by a genetic predisposition in their families.

Several studies note that many children with a dual-diagnosis had serious health problems that do not affect all children with Down syndrome. Children may be at increased risk of being diagnosed as autistic when they have experienced significant illnesses in early life including conditions such as infantile spasms, epilepsy, brain injury after complicated heart surgery, severe hearing or visual impairments and severe persistent infections. Not all children with Down syndrome who have these medical problems will become autistic but sometimes brain damage or serious sensory deprivation does lead to severe to profound levels of learning disability and autistic like profiles of development.

### Degree of learning disability

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<thead>
<tr>
<th>Level</th>
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<tbody>
<tr>
<td>Mild</td>
<td>IQ 51-70</td>
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</tr>
<tr>
<td>Moderate</td>
<td>IQ 36-50</td>
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<tr>
<td>Severe</td>
<td>IQ 21-35</td>
<td></td>
</tr>
<tr>
<td>Profound</td>
<td>IQ below 20</td>
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### Risk of over-diagnosis

The data in several studies provide evidence for the real risk of over diagnosis. For example, in a UK population study of 33 2-16 year olds with Down syndrome, 4 were diagnosed as having autism and a further 11 scored highly on items relating to ‘obsessional’ behaviours, such as liking routines, engaging in repetitive behaviours and disliking change.[6] These scores put them at risk of scoring in the autistic spectrum range even though they were not showing social or emotional impairments. Similarly, in the USA study of 20 children aged 2-3 years, 2 were diagnosed as having autism but a further 9 met some of the criteria – all of these demonstrated limited play, repetitive motor behaviours (particularly hand flapping) and were non-verbal at the time but none demonstrated a core difficulty in social relatedness.[7]

Many autism spectrum disorder questionnaires in common use include items covering language delay, motor ‘clumsiness’ and friendships which, if the user is not familiar with the development of children with Down syndrome, would lead to them scoring highly and being wrongly diagnosed.

### Regression at 2-4 years

In the USA there are specialised Down Syndrome Clinics in number of major cities led by specialist pae-
Daniel’s story

My son Daniel has both Down syndrome and autism. He was not officially diagnosed with autism till he was almost five years old. The delay with the diagnosis was not due to the lack of him having almost all of the symptoms for an Autism diagnosis, but due to the fact that he already had the diagnosis of Down syndrome and history of infantile spasms.

Daniel spoke his first word at ten months, and by two years old he had a vocabulary of twenty words. Then at two and a half he just stopped speaking; he did not even make vowel or consonant sounds. At first the doctor thought it could be seizure, like Landau-Kleffner; though Daniel still responded to us, he just did not speak. He had hearing tests, an EEG and multiple other tests but nothing was noted. Finally, after they took everything else out of the equation, it was determined that his lack of eye contact, his over sensitivity to stimuli, his self-stimuli body movements (rocking and flapping his arms), his odd play habits, and his lack of wanting any physical touch may be just what it suggests - Autism.

It is very hard to describe the problems of having the physical things associated with Down syndrome and the behavioral things associated with autism. I belong to both a Down Syndrome Association and the Autism Association, go to conferences and read all the books I can get my hands on, but we do not fit well into either group. I even had a Neurologist ask me why I would bother having the autism diagnosis added to the Down syndrome. The answer for that is what the school system offers for our kids. I had to fight to get them to use PECS with my child till they started to think of him as autistic. I am glad that someone has brought this subject up, since there are more children out there just like Daniel.

Laura Fontenot

To diagnose autism in children with a learning disability you need:

1. A detailed assessment of cognitive level (verbal and non-verbal) and of receptive and expressive language abilities
2. A developmental history covering progress from infancy onwards, preferably obtained with a standardised interview such as the Autism Diagnostic Interview
3. Observations of the child in both structured and non-structured settings (again a standardised instrument such as the Autism Diagnostic Observation Schedule Generic can be very informative
4. Routine screening for medical/genetic conditions
5. Consideration of other relevant psychosocial factors

Guidelines from Patricia Howlin 2000

Autism and Down syndrome

diagnosticians who see many children with Down syndrome. Two of these centres are making special studies of children with Down syndrome and autism. Both report that they see a number of children whose early development does not give any cause for concern but that they seem to ‘regress’ and lose some skills such as some early words or signs and then progress seems to stop and a serious autistic profile emerges. A vivid example of this pattern can be found in the case study of Andy written by his mother Joan Medlen on the Disability Solutions website. Cases which seem to indicate regression from an earlier ‘normal’ pattern of development are also seen in the general population of children with autism.

What conclusions can we draw?

At this stage, I am speculating based on my experience of children and what we learn from the published research. I think that it is probable that there are at least two groups of children with Down syndrome who are receiving the correct diagnosis of autism and Down syndrome, and another group who are wrongly diagnosed or may be ‘at risk’ for social withdrawal.

The two correctly diagnosed autistic groups do show deficits in social and emotional impairments in relating to and communicating with other children and adults. In one group, this autistic social impairment is seen in children who are otherwise functioning within the moderate to mild range of learning disability i.e. the typical range of IQ for children with Down syndrome. The second group have severe or profound levels of disability probably resulting from additional brain damage and are seriously impaired in most areas of their development.

The wrongly diagnosed group show a range of ‘obsessional’, repetitive,behaviours, may do some hand-flapping, may have limited play and dislike change and have limited communication skills but they relate affectionately to those around them. As their communication and play skills improve, the ‘autistic’ like behaviours will reduce though a tendency to cling to routines and show some ‘obsessional’ behaviours especially when anxious is very common among children with Down syndrome right through childhood years. However, if their communication and play skills do not improve, then children in this group may well withdraw and become more ‘autistic’.

Risk factors for social withdrawal

When children’s play and communication skills are developing very slowly due to learning disability, there is a risk that their development becomes arrested, or ‘stuck’.

For example, a child may sit and just roll a car back and forward, or line up bricks or sit and flap an object because he or she does not know how to play more creatively. Progress will only be made if someone – parent or sibling or teacher – plays with the child and shows him or her how to play in more rewarding and advanced ways. Even if play is not more advanced, if someone plays with the child, taking turns in a simple activity such as rolling a ball or running balls down a runway, this will prevent the child developing the habit of engaging in a repetitive activity that does not lead to any learning or progress.

A child who is not yet able to use some signs or words to communicate, and is of a shy temperament, may retreat into his or her own world and not seek out others to play with or communicate with. Sometimes such a child is making some efforts to communicate by reaching for something or by looking and these small communicative signs need to be encouraged. We need to be alert to any ways in which children are trying to communicate and to be sure we are giving them a chance to communicate and make choices. We should not fall into the pattern of doing everything for them and thinking for them so that they have no need to communicate. Most importantly, we need to be sure that every child with Down syndrome is receiving a service from a home-teacher or a speech and language therapist which focuses on helping parents to teach their child to progress in their use of signs and speech.
What can we do to improve diagnosis?

At present, we can draw attention to the guidelines already available from experts in autism such as Pat Howlin – see box on facing page. Her guidelines emphasise the need to consider the child’s level of cognitive and language functioning in order to be able to interpret behaviours in the context of the child’s current developmental level.

In adapting these excellent guidelines to be specific for children with Down syndrome, I would want to be sure that anyone assessing the child was aware that possible symptoms considered ‘autistic’ such as ‘obsessional’ repetitive behaviours, sensitivity to sensory stimulation and a dislike of change are common and not usually associated with any social or emotional deficits.

I would highlight the need to take a medical history first to identify any reasons to suppose the child has additional brain damage and also to screen for any existing conditions such as severe hearing loss or hypothyroidism or any conditions causing pain which have not been detected.

I would also encourage parents and professionals to wait until children are 5-6 years old to be sure about the diagnosis. They also need to be aware that most standardised autism assessments have not been evaluated for use with children with Down syndrome and should therefore be interpreted with caution. I would also encourage professionals to take parent’s concerns seriously as several recent studies highlight the fact that parents knew that their child was somehow different from other children with Down syndrome – but often no-one listened to them.

What treatments are effective for autistic children?

Despite the fact that the number of children with autism in the general population is increasing and that people have been looking for effective treatments for more than 20 years, there is no evidence that any treatment can ‘cure’ the underlying cause of the social impairment. There is some evidence that educational and management strategies may help children to progress, to adapt to their difficulties and to reduce the incidence of behaviour difficulties that they may show. The advice of Pat Howlin, based on many years of work in this field, is again a good starting point (see side box).

Each of these recommendations can be developed in more detail with examples of how they might apply to children with Down syndrome and autism. Space does not allow this here but more detailed practical information is contained in the forthcoming book on Atypical Development in the Dsii series.

In order of priority, the key messages for families are

1. Discuss your child’s additional needs in the family and recognise the extra demands that they make. Be sure to ask for the extra services you need including respite care. It may be helpful to link up with other parents in the same situation.
2. Develop a daily routine and a visual timetable to provide a structure, to allow the child to anticipate what is to be expected, and to reduce anxiety.
3. Focus on encouraging communication skills – however small the steps more communication will help. Remember to offer choices and respond to all attempts to communicate.
4. Focus on teaching independence and self-help skills as this will improve the child’s quality of life now and later.
5. Encourage participation in meaningful activities – such as helping with household chores. Children who have very limited abilities in play or self-occupation may be able to help with these, reducing the time they may spend in repetitive or ‘self-stimulating’ activities such as hand flapping or twiddling objects.
6. Engage children in play and activities with partners as much as possible – recognising that left alone they will not be able to make progress.
7. Try to limit the time spent in repetitive activities so that they do not ‘take over’.
8. As part of the daily routines, each of these recommendations could be developed in more detail with examples of how they might apply to children with Down syndrome and autism. Space does not allow this here but more detailed practical information is contained in the forthcoming book on Atypical Development in the Dsii series.

Features of successful intervention strategies for children with autism

- A combination of behaviourally oriented strategies with developmental and educational approaches relevant to the individual child’s profile of skills and deficits.
- Recognition of the need for structured teaching programmes, with a particular emphasis on visually based cues; these provide the child with a predictable and readily understandable environment, which helps to limit confusion and distress.
- A focus on the development of social-communication and play activities, especially with peers, and if possible the implementation of specialist training programmes.
- Acknowledgement that many so called undesirable behaviours are a reflection of the child’s limited behavioural repertoire or poor communication skills; a focus on skill enhancement is therefore often the most effective means of reducing difficult and disruptive behaviours.
- Understanding of the importance of obsessions and rituals, not just as an underlying cause of many behaviour problems, but also as having a vital role in reducing anxiety and as powerful sources of motivation and reinforcement.
- Treatment approaches that are family centred rather than exclusively child oriented.
- Management strategies that can be implemented consistently without excessive sacrifice of time, money and other aspects of family life.

Guidelines from Patricia Howlin 2000

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http://www.down-syndrome.info/library/periodicals/dsnu/04/03/
set clear expectations for behaviour
9. Use simple, clear and consistent language to maximise learning and understanding
10. Be calm in all your interactions – keep emotional expressions to a low intensity as displays of emotions that they sense but do not understand will increase children’s anxiety
A child with Down syndrome and autism should receive services from autism specialists who can help to address their extra needs.

The future
An intervention programme developed in Manchester which focuses on teaching social communication skills to autistic children at an early age has actually been shown to reduce the autistic symptoms of the children.[14] The team that developed this programme now have a large grant to extend their work. If we can identify the children with Down syndrome who have autistic difficulties early in their preschool years then similar approaches may help us to reduce their difficulties. We may have to accept that this may help the children in our first group most, those with autism within the typical ability range for children with Down syndrome. The children with severe or profound levels of disability, for whom an autistic profile is part of severe delays in most areas of their development, may benefit but will also need more help to develop their skills in all areas.

We need more research to enable us to collect detailed information on the ages at which the key social indicators of early social engagement with others such as pointing, following eye-gaze to both look at and imitate actions, emerge in children with Down syndrome. This might enable those with a real social impairment to be identified and supported as early as possible. We also need more detailed information on the ages at which communication skills develop so that we can spot the children with unusual difficulties.

We also need to know how severe hearing loss influences the progress in social relationships and communication in children with Down syndrome. I have seen children with Down syndrome and persistent losses of 40-60dB from ‘glue ear’ who have struggled with communication and had significant difficulties relating to those around them.

At the Down Syndrome Educational Trust, we plan to begin to collect preliminary data on these issues in the autumn on a representative group of preschool children attending our services, linked to the work we are doing on the Early Support Developmental Protocol (see page 138). We plan to apply for grant funding to support the full research programme needed to provide information on which to develop more effective support for this group of children and their families.

References

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Provision of coordinated care for individuals with Down syndrome: The Calgary perspective

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The benefits of a multidisciplinary/coordinated approach for individuals with Down syndrome

Introduction
In Calgary, Alberta, Canada, cooperation between families, agencies and health care providers has resulted in services that improve the health and quality of life for individuals with Down syndrome. One of these is the multidisciplinary Down syndrome team at the Alberta Children’s Hospital, which provides assessment, treatment and support to children with Down syndrome based on the established Down Syndrome Medical Guidelines.Originally established to provide services to children from birth to six years of age, the clinic now sees children until the age of 18 years. This change in clinic mandate has enriched and changed the practice of the team. They have an increased awareness of how issues develop over time and impact the child’s functioning and quality of life and have developed approaches to prevent and minimize these challenges.

This article describes the Down syndrome team’s evolution and the benefits of a multidisciplinary/coordinated approach for individuals with Down syndrome.

Down syndrome Clinic: The beginning
In the late 1980s a group of Calgary parents, in conjunction with community agencies and the Alberta Children’s Hospital (ACH) brought together a team of professionals to provide care to children with Down syndrome using the Down Syndrome Medical Guidelines as a framework for care. The team consisted of a Developmental Paediatrician, a Clinical Resource Nurse (CRN), a Physiotherapist (PT), Occupational Therapist (OT) and Speech-Language Pathologist (SLP), and operated within the Preschool Developmental Clinic at Alberta Children’s Hospital. The parent support group purchased a computer for the program and also provided funding to cover the cost of the nursing position. The initial pilot program involved 8 infants with Down syndrome and gradually the case load grew by approximately 12-13 infants a year.

In the early years, team members utilized their skills to address the child’s needs. It was assumed that the child’s medical needs were being addressed by the physicians involved, and the therapists focused on promoting skill development. The importance of regular medical follow up, and the use of the medical guidelines was encouraged, however, the responsibility for this was with the family, and contact between the team and physicians was primarily ‘one-way’, through written reports of therapy sessions.

The structure of the clinic meant that children were followed for a short time only. Upon reaching their sixth birthday, it was expected that therapy services would be accessed through the schools, and that community pediatricians would provide ongoing medical care as outlined in the Medical Guidelines. It was recognized that often the transition was not smooth, and that not all children were able to access care; however, the Down syndrome team, as part of the Preschool Developmental Clinic, was mandated to close files at the time of school entry. In view of these limitations it was concluded that a new service was needed.

Why was the Children’s Hospital chosen as the site for this service?
There were many advantages to having the team exist within the structure of Alberta Children’s Hospital. The hospital’s location, services and philosophy serve as the framework for the program.

The hospital provides service to Calgary area children from zero to 18 years of age as well as those who travel from southern Alberta, southeastern British Columbia and southwestern Saskatchewan. It is the only freestanding, exclusively pediatric facility and research centre between British Columbia and Winnipeg.

At the Alberta Children’s Hospital, a philosophy of family-centered care is promoted. It is recognized that children often heal better in their own home environment. That’s why many of the patients are seen as outpatients. In other words, they come...
Families are important members of the team in promoting health and wellness

having all these services under one roof allows the specialists to meet to discuss the child’s care, promoting a seamless service.

What changes have occurred over time?

Growth

Reorganization of hospital services in the 1990s brought about changes—most importantly, the extension of the team’s mandate to 18 years of age. Rather than discharging children from the clinic, we had the mandate to continue to follow them into adolescence.

With the increase in mandate, the clinic case load has risen to over 350 children (see Figure 1). As our city has grown, we have gone from 12-13 births a year to 25-26 and we are finding an increasing number of older children are being sent back to clinic by their primary physicians. As time passes, physicians from outlying areas are sending us an increased number of referrals as well, often urged on by parents or community therapists who have heard of our program. This growth brings a further challenge as team staffing levels have not risen in proportion to the caseload.

Staffing

Over the years, the team has been fortunate to attract additional professionals to provide care to children with Down syndrome. This includes a Social Worker, Audiologist, Clinical Dietitian, and an ear/nose/throat specialist.

In order to maximize limited resources and be responsive to the community, the linkages with the Down syndrome support group have been maintained and strengthened over the years. Decisions about staffing, mandate, and inclusion/exclusion criteria, for example, were made in consultation with our community partners, the support group, and families.

The support group also provides funding to allow the Clinical Resource Nurse to work a second day a week, and have been generous with funding to send team members to the Canadian Down Syndrome Society Conference on a yearly basis. They have provided funds to purchase toys and equipment for the clinic, and supply the materials for heel cups so that they can be offered to families free of charge.

Treatment challenges

Expanding service delivery to eighteen years of age revealed issues and concerns that the team had never dealt with before. Children were being referred because of behavioral and learning issues in the home and classroom, problems with sleep and toilet training, issues related to nutrition, weight gain, puberty, social concerns, and unresolved feeding issues. We were fortunate to have access to an enormous amount of research on Down syndrome, child health and development. We recognized that in addition to identifying and treating the problems, we needed to look at ways to prevent the problems from arising, provide education and support to families, agencies and schools, and educate other service providers. As members of the Down syndrome team, therapists began to gain experience and confidence in providing consultation to this population.

One of the most significant lessons we learned is that a person’s understanding of the impact of extra 21st chromosomal material is often based on misinformation or preconceived ideas. The Surgeon General’s report[21] (2001) referred to it as “diagnostic overshadowing” and commented that it continues to limit access to appropriate and quality care. The service team has learned that utilizing the Health Guidelines[7] does not always guarantee that issues are being identified and treated appropriately. If the individual believes that people with Down syndrome are ‘slow’, ‘handicapped’, or ‘unrealistic’ or ‘in denial’, they may not look beyond the ‘Down syndrome’ to identify the cause and treat it.

If certain issues are considered ‘normal’ for people with Down syndrome, they are often not investigated and can impact every aspect of the individual’s and families’ lives. Families have told us that when they have suggested that intervention was needed, they were often identified as ‘unrealistic’ or ‘in denial’.

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http://www.down-syndrome.info/library/periodicals/dsnu/04/04/
In our clinic, we often find health issues playing a role in the problems that bring the children to us. Children who have been sent to us because of behavioral concerns have made significant changes when we identified and treated their previously undiagnosed Obstructive Sleep Apnea; provided hearing aides to children who had undiagnosed severe hearing loss; provided suggestions to increase their ‘core strength’ when their low tone prevented them from sitting still in their classroom. Children who have lived with constipation for years have been diagnosed with Hirschsprung Disease, Hypoactive Thyroids, or been given strategies to manage their bowels successfully.

Experience has shown us that prior to any Developmental or Behavioral assessments, it is necessary to rule out possible health problems. We therefore do a complete nursing assessment by telephone when a child is referred to clinic. This assessment provides the family, hospital, community treatment programs, and schools. This information about the family, community and resources is obtained in order to insure appropriate therapies and supports are in place. Based on the information obtained, a plan is developed with the family and a package is mailed to them which includes consents, history forms, a Minnesota Infant Development or Child Developmental Inventory,[3] as well as information about the clinic and community resources.

When the signed parent consents have been received we are able to access information from the birth hospital, community treatment programs and schools. This information assists the team in identifying areas of concern, and planning their session to meet the needs of the child, family and community. Experience has shown us that these reports can reveal surprises – an echocardiogram that was not done; an abnormal echocardiogram that parents thought was normal, thyroid function tests that were not done and hearing reassessments that were missed.

With experience, our confidence began to grow, and we began to advocate more effectively for children in our care. Team members began to build linkages with other outpatient clinics, and utilize their expertise when problems came up.

Rather than relying on families to communicate with their physician, or that the physician would read our clinic note, the team began to contact physicians directly when concerns arose. Soon physicians were calling team members directly as well to consult about specific issues. Rather than separate individuals working in isolation, we began to see that working together we were more effective.

People with Down syndrome are complex, and need a team approach. This team ideally includes parents, family, caregivers, teachers, physicians, therapists, and community programs. The ability to meet as a group – whether it is face to face, via teleconference, videoconferencing, brings many benefits. These include a healthier child who thrives with appropriate interventions, treatments and program planning; a stronger support network for the child and family as they learn about the child’s needs and the resources they can use to meet them; and a resilient family who can articulate their concerns and advocate successfully.

The following case study demonstrates the way in which the service has met the needs of an individual family including a child with complex needs.

Case study

C.M. is an infant boy with Down syndrome, who lives in another Alberta city. His pediatrician, with encouragement from C.M.’s treatment team and his mother, referred C.M. to the Down Syndrome Team at Alberta Children’s Hospital when he was 14 months of age. The referral did not specify specific concerns, other than the fact that C.M. had Down syndrome.

Prior to the Clinical Resource Nurse contacting the family, the physiotherapist from C.M.’s treating team contacted the nurse directly to discuss her concerns. She indicated that according to parent report, “C.M. is able to roll; however, she has never seen this. He has very low tone, doesn’t reach, and primarily sucks his fingers. The team has concerns about his vision as well and feels that he doesn’t appear to process what he sees, and they are unsure if his vision had ever been checked. They also question his hearing and cardiac status. C.M. is able to drink from a spouted cup”.

The team had consent from C.M.’s treating team to send the Down Syndrome Team all available documentation, and was requesting a videoconference when our assessments were completed. The Clinical Resource Nurse contacted J.M. by phone to discuss her concerns. J.M. indicated her biggest concern was C.M.’s delayed development despite good health.

C.M. is the first child of J.M. and T.M. At 16 weeks gestation, J.M. expe-
rienced bleeding, and an ultrasound was suggestive of Down syndrome, which was confirmed via amniocentesis. C.M. was born via spontaneous vaginal delivery at 34 weeks gestation, and went to the Intensive Care Unit because of prolonged rupture of membranes. C.M. was reported to be healthy, with no allergies. He was taking a multivitamin and his immunizations were up to date. He has never received influenza vaccine. In the past, the family had tried Mineral oil and Lactulose to treat C.M.’s chronic constipation, but was now trying Catnip and Fennel in a glycerin base. He was given 2 ml from a dropper at every meal and 60 ml of Alovera Juice in his juice at mealtime. C.M.’s constipation has been a significant issue since solid food was introduced, and has been associated with rectal bleeding.

C.M. had an echocardiogram at nine months of age and was diagnosed with an Atrial Septal defect. J.M. understood that this would not have an impact on C.M.’s development, but was unsure about if and when follow up should occur. C.M.’s thyroid and blood count status was unknown, and by parent report they had not been checked since birth. There were no parental concerns about C.M.’s respiratory status, although it was noted that he appeared “bluish” around his eyes while sleeping. Vision and hearing had been screened at a year of age, however, audiology results were “inconclusive”, and although a “lazy right eye” was noted, no follow up was planned. C.M. had a circumcision done as a day surgery at the local hospital, and has had no other surgeries. By parent report, C.M. was at the 75th percentile for height and 50th percentile for weight on the Down Syndrome Growth Chart.

C.M. slept through the night at 3 months of age and typically sleeps with his back arched, head thrown back, or on his stomach or side. Mom reports that C.M. gets “hiccups” at least 6 times in 24 hrs. When asked to describe the “hiccups” she reported that if he is sitting up, he falls forward, eyes rolls back – describing it as a jolt. He then pulls back up and screams. If he is lying down, he gets “the same facial expression”, his arms jolt forward a bit, eyes roll up, grimace on his face. Other times he will have one “hiccups” then does “little jerks”. These episodes occur first thing in the morning, after his morning and afternoon naps, and wake him up about three times a night. J.M. had reported these events to C.M.’s paediatrician as well as his cardiologist and had been reassured. C.M.’s diet consists of Cream of Wheat with fruit for breakfast, 3 or 4 vegetables with chicken at lunch, sometimes rice, and supper is usually roast beef or chicken. Purees were introduced at six months of age and J.M. continues to puree all of C.M.’s food, as she reports that he chokes easily and doesn’t chew at all. He suks the food to the back of his throat so he can swallow it. He refuses Cheerios (chokes on an 8th of one) but can eat orange sections if the skin is removed, or Ichiban noodles if they are chopped.

C.M. was a “messy” breast feeder, and often chokes on liquids, especially if they are given by spoon. Despite the choking episodes, J.M. feels that C.M. can adequately protect his airway, and reports no history of respiratory illnesses or pneumonia. C.M. is not an independent feeder as he is not yet reaching for objects, and has recently started to poke at his food while being fed. The only thing he brings to his mouth is his hands and sucks on his fingers while being fed to help move the food back in his mouth. C.M.’s central lower incisors erupted at fifteen months of age, and he appears to be teething again. He gets mad when his mom goes near his face with a toothbrush and will only open his mouth to a spoon.

C.M. receives bi-weekly therapy services in the home from Occupational Therapy, Physiotherapy and Speech-language Pathology. Although the family is eligible for special needs funding support, they have not accessed this resource. They have limited opportunities to access respite, due to financial restraints, and C.M.’s high needs, although family members will assist occasionally.

Based on the phone conversation with J.M., the following issues were identified:

1. ‘Hiccups’ - are these infantile spasms?
2. Developmental delay – is this reflective of more than Down syndrome? Are the ‘hiccups’ related?
3. Feeding/swallowing/chewing difficulties – at risk for aspiration?
5. Hearing status.
6. Health status – needs blood work as per the Down Syndrome Medical Guidelines, including CBC and Free T4, TSH.
7. Cardiac status – need to review documentation to determine need for further follow-up.
8. Herbal remedies – are they safe and appropriate?
9. Chronic constipation.
10. Possible Obstructive Sleep Apnea – unusual sleep position, blueuness around eyes, developmental delay, restless sleep.

The following plans were made in consultation with the family:

1. Clinical Resource Nurse advised a.m. that her report of ‘hiccups’ was of concern, and further investigation of these events needed to be done. The Clinical Resource Nurse will review the information with the Developmental Paediatrician and will contact referring physician with our concerns and suggestions.
2. Family in agreement with referrals to Neurology clinic, Ear Nose and Throat Clinic (ENT), Gastroenterology, Surgical, Dentistry and Sleep Clinic if Developmental Pediatrician feels appropriate.
3. Clinical Resource Nurse will contact C.M.’s treating team about ‘hiccups’ to determine if they have witnessed them and ask them to follow up.
4. Clinical Resource Nurse will arrange for Social Work, Developmental Pediatrics, Ophthalmology, and Audiology appointments as soon as possible, as well as Neurology, Sleep Clinic, ENT, and Gastroenterology if Developmental Pediatrician in agreement.

Following medical work up, arrangements will be made for a feeding and developmental assessment with Down Syndrome Team Occupational Therapist, Physiotherapist, Speech Language Pathologist.
5. J.M. will advise Clinical Resource Nurse if the family will need accommodation at Ronald McDonald House. At this time, they prefer to stay with extended family in the city.

After reviewing the above information with the Developmental Paediatrician, the appointments and referrals were arranged as per the above plan. Over the next few months, this family made numerous trips to Calgary for assessments and follow-up. Neurology saw C.M. on an urgent basis, an EEG was done, and the ‘hiccups’ were diagnosed as Infantile Spasms. A short time later, partial seizures were noted as well. An MRI under general anesthetic showed delayed myelination. Controlling these events has proven to be extremely difficult, and although parent report indicated an improvement, the EEGs did not change.

Currently, C.M. is undergoing a trial of ACTH and a follow up EEG has demonstrated a response to the drug. He will continue to receive injections every other day, and will then be weaned off over a three month period. Recently, C.M.’s family and treating team noted that he was exhibiting autistic-like behaviors and is increasingly irritable and difficult to console. Eisermann, DeLaRaillere et al,\[14] have reported a statistically significant correlation between treatment lag and lag to cessation of spasms, developmental quotient and score of autistic features. They found that the later the response to treatment of infantile spasms, the lower the developmental quotient and the higher was the score of autistic features. A long duration of spasms also determined a low developmental quotient and a high score of autistic features. Resources have been put in place to increase this family’s access to respite, and strategies to manage C.M.’s behaviors have been developed.

C.M. was hospitalized in his local hospital with pneumonia shortly after the telephone interview, therefore a Videofluoroscopy was arranged on an urgent basis and confirmed that C.M. is a silent aspirator. A Nasogastric tube is now utilized for fluids, and oral feeding is limited to thick purées. His parents have decided to pursue a Gastrostomy, however, further testing to rule out Gastroesophageal Reflux will be done prior to this surgery. This will necessitate an inpatient admission, as he will need to have his Nasogastric tube removed for 24 hours prior to the x-rays and will require intravenous fluids. Given his immune-compromised status, this will be postponed until his course of ACTH is finished. If reflux is identified, C.M. will have a Fundoplication done at the same time as his Gastrostomy.

Hirschsprung Disease was ruled out with a rectal biopsy; however C.M. was diagnosed with bilateral undescended testes. Surgery is planned for a later date, following stabilization of his seizures and feeding issues.

C.M.’s parents received some positive news as well. Although C.M.’s screening for sleep apnea (pulse oximetry) raised concerns, his polysomnography was normal, ruling out Obstructive Sleep Apnea. His vision and hearing were within normal limits, and will continue to be monitored on a regular basis.

C.M.’s TSH was found to be 6.34 mU/L and Free T4 14 mU/L, and so he was referred to the Endocrine Clinic, who felt the results were influential to C.M.’s seizure medications, and will continue to monitor his thyroid status.

Review of C.M.’s cardiology consultation report confirmed that C.M. has an Atrial Septal Defect, and suggested follow up by a cardiologist should be at the physician’s discretion. No antibiotic prophylaxis is indicated.

Independently, C.M.’s parents decided to stop using herbal therapies, as they did not feel they were beneficial in addressing the constipation issue. C. M. was reviewed by Paediatric Dentistry and was found to have no caries.

The Down syndrome team completed developmental assessments and provided the treating team and family with information and suggestions. C.M. is presenting with significant delays in all areas of his development, as well as some autistic-like features. Further monitoring and assessment (particularly when the seizure activity and aspiration issues are resolved) will hopefully assist in determining what the future will hold for C.M.

The use of live videoconferencing has allowed the family and involved professionals to meet “face to face” to share concerns, ask questions, and plan care over a long distance. The result is less traveling for the family, and increased knowledge and confidence for the professionals. The long term goal is that C.M. (as well as other children with Down syndrome) will have the opportunity to access the resources they need in their own community.

C.M.’s experience highlights the complexity of health issues that people with Down syndrome may have and the importance of looking beyond the diagnosis of Down syndrome. Although C.M. was living in a metropolitan area and accessing medical and therapeutic specialists, a number of health issues were unidentified which impacted not only C.M.’s health, progress and prognosis, but his family as well.

Future directions

Currently, only individuals under 18 years of age with Down syndrome can access the team’s services. There is a high need for an adult clinic to provide coordinated care, and support individuals and their families as they move from pediatric services to the adult world. The development of an Adult Clinic would also provide professionals with the opportunity to develop expertise about adult issues, and perhaps strategies to reduce the problems through intervention earlier in the lifespan. At this time, the Adult Clinic remains a dream, but not an impossible one.

Glossary

**ACTH:** Also known as Prednisone, Cortrosyn. These are anti-inflammatory, steroid medications that are used to treat a number of neurological conditions including infantile spasms, Landau-Kleffner syndrome and certain cases of Lennox-Gastaut syndrome.

**Antibiotic prophylaxis:** The administration of antibiotics in order to prevent possible infection.

**Atrial Septal defect:** A hole in the wall that separates the two atria (receiving chambers) in the heart.

**CBC:** Complete blood count.

**Free T4:** That proportion of thyroxin (T4) which is not bound to carrier proteins, and floats freely in the blood. It is less that 1% of the total blood T4.

**Fundoplication:** Surgery to that part of the stomach adjacent to the...
Provision of Coordinated Care for Individuals with Down Syndrome: The Calgary Perspective

oesophagus to treat gastroesophageal disorder.

Gastrostomy: The placement of a feeding tube directly into the stomach through the abdominal wall.

Minnesota Child Development Inventory (CDI): This tool is completed by the parent and measures the child’s development in eight areas: social, self-help, gross motor, fine motor, expressive language, language comprehension, letters, and numbers. It also includes a General Development Scale and 30 items to identify parents’ concerns about their child’s health and growth, vision and hearing, development and behavior.

Minnesota Infant Development Inventory (IDI): This tool is completed by the parent and measures the infant’s development in five areas: social, self-help, gross motor, fine motor and language. Parents can also report any questions or concerns about their baby’s health, development, or behavior.

Myelination: The process whereby nerves are covered with a myelin (complex fat) sheath during development.

Polysomnography: The simultaneous measurement of several physiological indices such as blood gases and air movement during sleep.

Video fluoroscopy: The filming of moving X-rays onto videotape.

References

This paper was presented at the 8th World Down Syndrome Congress in Singapore, 14-18 April 2004.

Atlantic Ocean - sponsored inclusion crossing 2005

Would you or your organisation - or one you know of - be interested in sponsoring the CSIE Atlantic Challenge - Inclusion Crossing?

The tall ship Tenacious, owned by the Jubilee Sailing Trust in Southampton is sailing the Atlantic this autumn with a crew of able-bodied and disabled people, and Mark Vaughan OBE, Founder and Co-Director of the Centre for Studies on Inclusive Education, will be joining this crew on behalf of CSIE for the month-long trip.

The 3,000-mile crossing is from the Canaries on the trade winds to Antigua in the West Indies. A Declaration for Inclusion signed by a number of UK organisations and calling for fully supported inclusive education for all pupils, will be carried on the journey. On arrival in Antigua, this Declaration will be despatched to the United Nations in New York in a bid to influence the education section of the new, draft UN Convention on the rights of disabled people.

CSIE hopes that you will be able to support this fundraising, inclusion adventure, and we look forward to hearing from you in due course. Please see www.csie.org.uk for more information.

The Special Olympics Great Britain National Summer Games will be held in Glasgow between 1 – 9 July 2005. This is the largest sporting event to take place in Britain for people with a learning disability this year. Almost 3500 athletes and coaches from 19 regions throughout Great Britain will be taking part, plus invitation teams from Ireland, Germany, Spain, Poland and Holland.

Special Olympics’ mission is to provide year-round sports training and competition in a variety of Olympic-type sports for people with learning disabilities, giving them the continuing opportunities to develop physical fitness, demonstrate courage, experience joy and participate in a sharing of skills, gifts and friendship with their families, other Special Olympics athletes and the community.

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Kirsty is a beautiful, lively three-year-old. Kirsty is loving, kind and at times cheeky. Kirsty loves “Noddy” and “The Tweenies” but she is not so keen on “Teletubbies”. Kirsty is my daughter and she happens to have Down syndrome.

For my wife, Janet, and I having Kirsty has been the most wonderful experience. She has brought us great joy and like any parents we could not now imagine life without her. Of course when we were told our as yet unborn child had Down syndrome we were devastated. For me, the dreams of my child and her future were shattered – even worse when we were told she had duodenal atresia and a VSD. How would we cope? Were we strong enough to cope?

For us there was no question of not allowing the pregnancy to proceed – it was just a matter of trying to prepare ourselves. Looking back, knowing Kirsty had Down syndrome prior to the delivery was hard but it did allow us to come to terms with the situation and we had many special moments – feeling her kick, seeing her move on the many scans Janet had. We accepted her completely – this was our baby.

When she was delivered (by emergency C-section as is tradition for most medics babies!) she came out screaming and decidedly annoyed at being disturbed. She had her duodenal atresia repaired that day and we took her home after 12 days. We were thrilled.

We had a meeting with the community paediatrician who chatted about services and the importance of ‘Early Intervention’ to maximise developmental potential – we saw the physiotherapist within Kirsty’s second week and she visited us weekly in the early months. We had useful support from the Down Syndrome Association and we read books – some by professionals, some by parents. Our families were learning too, but mainly we were all getting to know Kirsty.

Kirsty developed heart failure almost immediately and we syringed diuretics into her twice daily until she grew a bit bigger. Spironolactone tastes foul and to this day she still goes crazy if we try to give her calpol from a syringe! Her VSD was repaired at 8 weeks and then we realised how poorly she had been because now we had a baby that had the energy to scream the house down (a little known side effect of making a baby better!).

Much has happened since those early days. We moved to Sheffield when Kirsty was 2. By then she was babbling away happily. We have used Makaton signing to communicate with her since she was a baby. It is a great way of augmenting spoken language and it has actually been shown to speed-up acquisition of language skills. Kirsty now has about 70 signs which she uses or recognises. She is not talking yet because of a conductive hearing impairment but one day soon we know it will happen and when it does – just like when she took her first steps – we will cry and jump for joy at the same time.

We attended a course early on at the Down Syndrome Educational Trust in Portsmouth. The importance of starting early was emphasised, as was the relative strength of children with Down syndrome in learning more visually than through auditory memory – hence the importance of Makaton.

Recently I was chatting with a colleague about our families and when I told her Kirsty had Down syndrome she said “I’m sorry”. I think it just came as fairly unexpected news to her and this was her first reaction – I wasn’t upset. Perhaps I even knew why she said it – paediatricians regularly have to deliver upsetting news to parents and it would not be surprising if the words “I’m sorry” are used in that situation. She had transferred the phrase to our social chat. But it made me think about what we as doctors say to our patients and their parents and how important our
words are.

I still remember the cardiologist who told us that we were brave having our baby because of how difficult things would be as she got older – I can remember the words exactly while I’m sure he forgot his words almost immediately. How many times have I heard professionals’ thoughtless phrases and clichés: “he suffers from Down syndrome” or “he is a Downs” or “children with Down syndrome are all lovely and enjoy music”… the list goes on. My point is we as professionals need to be careful what we say and how we say it – it really matters to parents and our patients.

Having a child with Down syndrome is not a disaster – certainly it was a shock to discover the diagnosis but ultimately it really is not the end of the world. And as the parent of a child with a learning disability, I do not feel brave and I do not want anyone to feel sorry, either for me or more importantly my daughter. Of course, if someone were able to take away the extra chromosome I would say yes, but this isn’t going to happen.

Kirsty has Down syndrome but this does not define her as a person – it is part of her but there is so much more to our little girl. Her personality shines through and she has achieved so much in her 3 years. I am optimistic about her future. Kirsty, like most children with learning difficulties, will go to mainstream school and with the correct level of support this will be a success. A recent issue of the Down Syndrome Scotland magazine featured a teenager proudly holding his GCSE certificate. Many adults with Down syndrome live practically independent lives – working, socialising, having relationships. An individual with Down syndrome has the opportunity now to achieve so much more than even 10 years ago and as the beliefs/prejudices of society are challenged so much more may be possible in the future.

I said at the beginning of this piece that my dreams were shattered when I knew Kirsty had Down syndrome. Well, since then new dreams have emerged – I want Kirsty to be happy and to achieve her full potential. Only now I realise those dreams are identical to the ones I had before I knew about Kirsty’s Down syndrome. After all, at the end of the day all any of us want is for our children to be happy and achieve their full potential.

Kirsty’s dad, Neil, is Specialist Registrar in Paediatrics at the Sheffield Children’s Hospital. In this short article, originally printed in the Sheffield Paediatric Reader, March 2005, Volume 10, Issue 3, he highlights the importance of the way in which health professionals communicate with parents, both at diagnosis and in the future. A recent large-scale survey in the US collected data from mothers of children with Down syndrome, many of whom reported that their “physicians talked little about the positive aspects of Down syndrome and rarely provided enough up-to-date printed materials or telephone numbers of other parents with children with DS”.[1]

Len Leshin’s website features this research in his ‘abstract of the month’ section as he says, “something good has come from [it]” in the form of a new US bill called the “Prenatally Diagnosed Condition Awareness Act.” (S. 609) which states as its goal:

“To amend the Public Health Service Act to increase the provision of scientifically sound information and support services to patients receiving a positive test diagnosis for Down syndrome or other prenatally diagnosed conditions.”[2]

The full bill can be accessed online at http://thomas.loc.gov/ by searching for bill S.609. This bill does not however cover the way in which post-natal diagnoses are communicated to parents.

Neil says that in his experience in the U.K., “most paediatricians are pretty enlightened – with some exceptions – but … I have a real worry about the quality of counselling received by many couples being given an antenatal diagnosis of Down syndrome. In my experience obstetricians see Down syndrome as a condition to be screened for and termination would follow if a positive result is found. The fact is the majority of couples having an antenatal diagnosis go on to terminate and I think this largely reflects the bias/ignorance of the professionals involved in counselling. One solution is to get paediatricians involved in the counselling process as they can give a more balanced view on the health aspects, while the DSA/DownsEd etc can give the reality of life with the child. I am deeply uneasy about the ethics of screening for Down syndrome because by offering screening we are telling prospective parents that Down syndrome is “bad” and any baby with it should be rejected. Proponents of screening say antenatal diagnosis allows the couple to adjust prior to delivery – as in our case with Kirsty – but the fact remains we are in the minority of couples who chose to proceed with the pregnancy. I feel strongly that in some way the balance needs to be redressed. I guess we all need to keep plugging away at prejudice and challenging unacceptable views of Down syndrome.”

It is clear that health professionals, especially those in maternity, need up-to-date knowledge about Down syndrome regarding short and possible long-term outcomes and sources of support. To this end, the Trust has sent information packs to every maternity ward in the UK. We also provide ‘New Baby’ packs to parents on request.

Professionals who would like more information to inform their interactions with parents are advised to download our publication Living with Down syndrome from www.down-syndrome.info/library/dsii/01/01/DSii-01-01-ENG.htm which gives a positive and concise overview of the influence of Down syndrome on development over the lifespan. Our website also provides details of our forthcoming training events at www.downsynd.org/news/events/

References

My dream came true: Everyone is the same human, same life

Aya Iwamoto
Japan Down Syndrome Network

I have Down syndrome. I graduated from Kagoshima Women’s University in the Department of English Literature on 20th March in 1998. The commencement was the best day of my life that my dream came true. In the month of May, I made a speech by English at the 3rd Asia Pacific Down Syndrome Conference which was held city of Auckland in New Zealand.

I obtained a librarian’s license in 1999. I’m studying French and English conversation at Shigakukan University of my alma mater as an auditor now. Besides studying foreign language, I’m making a speech and exchange about Down syndrome and I’m asking many people for an understanding. I want to introduce this impressionistic essay.


I made a presentation of these experiences at the 8th Down Syndrome Conference in Singapore.

My personal history

First, let me tell you a little about myself. I was born at Kagoshima University Hospital in 1973. My birth must have been a very big joy for my father and mother. However, I developed jaundice and was put into an incubator for about two weeks. When we were leaving hospital, the doctor told my mother that I had Down syndrome. My mother says that she can’t remember how she got home after the shock of hearing that.

I had complications: heart trouble and pyloric stenosis. Pyloric stenosis is a narrowing of the pylorus, which is the outlet from the stomach. This makes it hard for any food, even milk, to leave the stomach. As a result, when I had a cold, I often vomited my food like a fountain, even my mother’s milk. I would vomit repeatedly when I was lying down, and my mother often had to sleep leaning against the wall while she was holding me.

I went to a Montessori Catholic kindergarten when I was a child, and I enjoyed the comfortable, carefree environment there. But before I entered elementary school, I often had to sit down and rest. An examination at Kagoshima University Hospital showed that I had hypothyroidism, a condition in which the thyroid, which is an organ located in the front part of the neck, makes too little thyroid hormone. As my symptoms were becoming more serious at that time, we moved to Hayato, a town with hot springs and very pleasant surroundings, to take a rest from Kagoshima City.

I was in ordinary classes through elementary and junior high school. I passed an entrance examination for an ordinary public senior high school and graduated three years later. I then entered Kagoshima Women’s University, which was my dream, and have now graduated.

Taking part in the 3rd Asia Pacific Down Syndrome Conference

I’ve changed a lot since I took part in the 3rd Asia Pacific Down Syndrome Conference, held at Auckland, New Zealand, as a representative of Japan. As one of five members on a panel at the conference, I spoke in English about my experiences. I was very nervous when I found myself standing on the stage at that international conference, but I was able to finish my 15-minute speech in spite of feeling all through the speech that I couldn’t breathe. When I received a standing ovation, I felt very happy. It really boosted my confidence, and I’ll never forget that experience as long as I live. The following is a part of my speech:
I graduated from Kagoshima Women's University in the Department of English Literature on 20th March this year. The commencement was the best day of my life. I will never forget it. After representatives of the different departments received degrees, the President of Kagoshima Women's University, Mr. Sunagawa, congratulated the graduates. He mentioned me in his speech. He said, “It is a very wonderful that there is Miss Aya Iwamoto in the graduated students. Her intense figure made a deep impression and courage on the many school-mates. That must gave a hope and encourage people who have same handicap. Her effort is wonderful. It is our pride to assist her studies.”

I was deeply moved by his speech, and tears came to my eyes. My parents shed in tears, too.

It’s my dream to become a librarian in a quiet library. I am studying French, too. I want to go and see the pictures in Le Musee du Louvre and Le Musee d'Orsay in France. My hobbies are listening to music and looking up words in the dictionary. Today, I am going to talk about my personal history book.


I have been sick since I was born, and my parents have had a lot of trouble. I grew up without knowing much about my illness. When I was in my second year at university, I learned for the first time that I have a handicap. While I was watching a program about Down syndrome on Japan’s NHK television, I asked my father about it, and he told me I have Down syndrome. I had suspected something like that, but it was a great shock for me when I was told. My mind went blank. Then I saw my mother writing about my illness on a word processor. It really surprised me, and I didn’t want to believe it. I was very sad.

I learned that my parents were going to publish my personal history in a book, making my illness public and telling about our family life. I worried about it, and I didn’t want them to reveal my illness. I cried bitterly. My father and mother said, “You have done wonderfully. Don’t be afraid. Take pride in yourself.”

I talked about my worries to Dr. Tanaka, who works at the Child General Consultation Center in Kagoshima City. He said, “It is very important that you tell about your handicap.” At first, I didn’t think I could tell everybody the truth, but I was encouraged by his words, so I made up my mind not to try to hide my condition anymore. Also, my relatives and my parents’ friends encouraged me. I’m not afraid any more, and there’s no need to hide the truth.

I want many people to read this book that my parents have published. I’d like them to understand the feelings of the handicapped. The book has finally been published. We got a lot of letters and telephone calls from all parts of Japan. People said that the book was deeply moving, that my example gave them courage, that they cried reading the book, that they found hope for the future, and so forth. We were encouraged by their messages. I think that it was a very good thing that my parents published this book.

I also hope to work with handicapped children. I have a lot of dreams.

People have a shallow view and prejudice against Down syndrome in Japan now. It’s a pity. Life is short, but precious. That’s why I won’t give up my hopes and dreams. I am grateful to the many people who helped me, and I want to say to my parents, “Thank you for giving birth to me.”

My talk and exchange trip

I have continued giving lectures and taking part in exchanges all over Japan since I graduated from university. I’ve given a lot of lectures, in junior colleges and universities and at nursing school festivals. After the lectures, people in the audience have written their impressions in very moving essays. Their words were simple and kind-hearted, and they encouraged me and moved me deeply. Many people have attended these lectures all over Japan. There were 1500 people in attendance just in Okinawa. Senior high school students in particular attended, and they listened intently to my speech. After each lecture, the lobby was crowded with students, and they asked me about everything. Recently, in the Shimin-Kaikan hall of Fukushima Prefecture, the audience included students from junior high school, senior high school and a nursing school.

Writing their impressions of the lecture, they mentioned their own ideas and goals in life right now and how their points of view on Down syndrome, handicaps, prenat al diagnosis, etc. had changed.

I’m so glad that young people show such understanding. Many people have written me over these five years, and I have met many wonderful people, too. It has been an irreplaceable fortune for me. I’d like to share with you one mother’s words which I will never forget. She said “Today, I learned about your speech from the newspaper and was able to attend your lecture. My child has Down syndrome, too. When we were first told of it, we were greatly shocked. We were at a loss to do and how we could raise our child. Actually, our child is in hospital, and we aren’t raising her, but I was listening to your talk today and I felt a little relieved to hear what you said. On raising children, it should make no difference to the parent whether the child has a handicap or not. I want to accept my child as she really is; I won’t compare her with other children, I will just bring her up naturally. This is my idea today. I think we ourselves, the parents, can continue to grow, by bringing up our children, by finding things of value in our children. Today was a wonderful day.”

When I made a lecture tour of Japan, I met many people who had been suffering from social discrimination and prejudice. I met a mother who has a baby with Down syndrome in Shimane. Her baby has a serious heart disease and when she was trying to arrange for an operation, the doctor of a famous university said, “It is useless to operate on your daughter. Children with Down syndrome don’t know their parents’ faces, anyhow.” She was very shocked at what he said. I thought it was very terrible, too, when I heard about it.
Her mother told me in tears, “I saw you on a television programme, and I was so pleased!”

**Everyone is the same human, same life: About prenatal diagnosis**

I became a member of Japan Down Syndrome Network (JDSN) and came to know about the problem of prenatal diagnosis. I also learned of the triple-marker test, which tests for three handicaps, including Down syndrome. The problem is that such procedures deny people with Down syndrome the right to life. Whether one has a handicap or not, all people are equally human, with the same right to life; there is no difference in the importance of different people’s lives. Human lives are equal in importance. Many specialists, doctors and the parents of children with Down syndrome started a movement to submit a petition to the Ministry of Health and Welfare (the present Ministry of Health, Labour and Welfare)’s committee. I also submitted the petition two times myself. No person with Down syndrome had ever presented this petition before. After one lecture that I gave, a third-year senior high school student wrote on her questionnaire the following very moving reaction. She said, “I have been thinking about prenatal diagnosis. I felt that unborn children can’t even think for themselves; whether they have handicaps or not, they don’t even realize that they are alive. But then Miss Aya said, ‘Thank you for giving birth to me,’ my old way of thinking completely disappeared, and I felt very ashamed of myself. What is important is not to get rid of handicapped children, but to find a way to live well with them. I need to think about how handicapped children can have good lives. From now on, I hope to show the people that I come in contact with how precious they are.”

I was deeply moved by her message. I hope many people will come to feel the same way.

**My dream came true**

When I was a child, I could see from my house the white buildings of Kagoshima Women’s University high on a hill, and I longed to go there. I had a dream of entering and graduating from Kagoshima Women’s University. I was able to realize this dream. I studied about children’s rich imagination, human kindness and love. These became the theme of my graduation thesis. Next, I had a dream of trying to do something connected with these interests of mine. When Dr. Yukihisa Matsuda, a pediatrician, asked me, “Aya, could you put my Maho no Drop into English?” I had both high hopes and some uneasiness. Still, I decided to try to translate the book into elementary English in order to move closer toward achieving my dream. I was able to translate this book into English, and it was published in October, 1999, as *Magic Candy Drop*: Story by Yukihisa Matsuda, illustrated by Yasuko Kuroda, translated by Aya Iwamoto. This achievement brought me great pleasure. I would like to introduce part of this book.

One night, he hears something.
“Ken, Ken.”
Ken wakes up and looks about.
“Hi, Ken.”

“Huh? Who are you?”
There is an ant behind one wheel of his wheelchair.

“Thank you for all the bread you give us. We are going to have a party next Sunday. Our queen ant really wants you to come.”

“Really?” “I’ll wait for you under the poplar tree. Don’t forget.”

The ant went home. Ken pinched his cheek.

“Ouch! This isn’t a dream. I want to go to the ant’s house, but my doctor will not permit me to go out.” There is a check-up every morning in the sanatorium. Ken’s doctor has a mustache. Children call him Dr. Kuma.

“Morning, Ken. How are you today?”

“Fine, thank you.”

His doctor is listening to Ken’s throat and chest with a stethoscope. He also examines the back of Ken’s throat with his penlight.

“O.K! You’re in good shape!”
Ken smiles. Then, he tells the doctor about the ant he met the previous night.

“O.K. I’ll give you permission to go out. The ant’s house is dark, so it will be good to take this.”
He puts his penlight in Ken’s pocket. On Sunday, Ken puts on his hat and happily wheelchair to the Poplar tree. The ant is waiting for him. The ant’s house is in a hole in the poplar root.

“Hey, we can’t get into that small hole!”
Ken looks a little worried.
My dream came true: Everyone is the same human, same life

I’m studying French at university now, and I’m interested in French culture. I want to travel around and visit museums, too. It has been my dream for many years to travel to France with my family, and we were able to go there in June, 2000. I visited Le Musee du Louvre, Le Musee d’Orsay and Le Musee Marmottan, which has a collection of the works of Monet, my favorite painter. Paris is a very beautiful historic town.

In January, 2001, I published my travels in Paris as Yumetsumugu Aya (meaning: Spinning Dreamer Aya) jointly with my mother.[2] In the same year, I got a request for a translation of a Canadian fairy tale, How Smudge Came: story by Nan Gregory, pictures by Ron Lightburn, translated by Aya Iwamoto, from the Akane Shobo publishing company in Tokyo,[3] I was able to publish a second fairy tale book in June. I felt highly honored to be asked to translate this picture book, written by such an excellent author, who has received an award in Canada for his writing.

Another dream of mine is to translate and make a picture book for a French fairy tale so that it could be read to and heard by many children, especially handicapped children. I also still want to be a librarian.

Let me mention one more of my dreams. I want to translate into Japanese some interesting children’s picture books from Singapore.

Finally, I want to say once more to my parents, “Thank you for giving birth to me.” And, I hope peace will come to the whole world.

I’m studying French at university now, and I’m interested in French culture. I want to travel around and visit museums, too. It has been my dream for many years to travel to France with my family, and we were able to go there in June, 2000. I visited Le Musee du Louvre, Le Musee d’Orsay and Le Musee Marmottan, which has a collection of the works of Monet, my favorite painter. Paris is a very beautiful historic town.
Rhiannon was born 2/9/98 and weighed 5lb. 6oz. She is now 6 years old, she’s lovely with long golden hair. She has two brothers, Neil, 20, and David, 17. She attends a small village school with full-time 1:1 support.

Rhiannon has had lots of little health problems – she has constant colds, coughs and sticky eyes. She is still in nappies although she is just starting to sit on the toilet. She wears glasses and keeps them on – she has a sports band attached so if she does take them off we don’t lose them. She has grommets now, but it took two years for her to have the operation and her hearing was really bad. I feel she was nearly deaf for at least one winter – we always seem to be at the G.P. or hospital and things seem to move slowly, but I do understand her little ways now and know what to do and ask for.

Rhiannon struggles with communication; she doesn’t talk. She did Makaton when she was younger (18months – 2½) but then she seemed to lose interest, but she lost interest in most things and went in to her own little world. We have now started ‘Pecs’. She really seems to like it, so we will keep going.

At the moment we are looking into special school as we feel she needs specialist help with her communication. We are hoping to have a dual placement.

Rhiannon is a lively little girl; she loves the outdoors, the beach, swimming, running around – not with her peers yet. She is well-behaved – I can take her in to a shop and she will hold my hand and walk nicely. She knows her day routines and is able to dress and undress herself with help. She likes videos – her favourites are Brum, Tweenies and the Makaton signing video. She also likes musical toys and books.

She hardly ever cries and always has a sweet smile full of mischief. For all the struggles she has, we love her to bits.

*Ruth and Carl Rogers*
Cheshire, UK
Joseph’s book-keeping

Nicky Gregory

Parent, Hove, UK

Joseph’s not that keen on reading books, but he takes after me in a penchant for recording things. He’s pretty computer literate and likes to check out the Liverpool website daily (he’s a Liverpool fan). He also checks out the Eastenders website and one time, off his own bat, started copying out some of the story line.

We’ve always lived just a few hundred yards from local shops and he became competent enough at crossing roads from fairly young, so we encouraged him to go to our local corner store with a list to buy a few things, from time to time. We swapped phone numbers with Nick, the storekeeper, which was a very good idea: he phoned us up when Joseph turned up there without our realising he’d gone out, and wanted to buy some videos.

Some time ago, when Joseph’s list of consumer wants moved up an octave in expense, from sweets and football stickers, to CDs and computer games, we realised that instant gratification had to stop.

I gave him a little notebook – really little, about 3 in. x 5 in. and slim – that could slip in a pocket, and a pen, so that he could make lists of things he wanted to buy, with their prices. When he comes home he can talk about them with us or his brother, who’s a couple of years younger and very suss about computer games and CDs and all things electronic.

Now we’re trying to get him to keep track of his spending when he goes out with our lovely young respite carer. At the moment I’m writing the basic template:

Starting Money:
Money spent:
Money left over:

Money spent + money left over = Starting money

There’s a gap under money spent for him to write in all the different expenses, for example, bus fares, café, snooker or cinema or presents bought. The idea is that he writes the expenses in as he goes and/or saves the receipts and does the sums at the end to check that he’s included every-thing. He does still need help with the sums.

I think we need to talk with him about it more, talk about comparing costs. We’re going to be meeting with a Direct Payments adviser soon: he’s just 18 and we’re preparing for Joseph to be able to handle income himself. At the moment we give him money on an ad hoc basis.

He has 2 bank accounts and goes online to check them. There was a bit of difficulty about that. My husband, Jon, sorted it out over the phone. He has a current account and a deposit account. When he earns some cash, for example from cleaning cars, or gets some for a birthday or Christmas, he goes round to the local building society branch and pays it in. He then comes home, goes online to check it’s in that account and then transfers it to the deposit account. For some reason he can’t pay it in directly to his deposit account. His current account has a cash card and he can transfer money from his deposit account to his current account when he wants to go and buy something. Jon helped him by writing down the things he has to key in, password, number etc. That’s on a piece of paper in a special drawer – he’s very organised like that, in fact more than our 16-year old without Down syndrome, who has dyslexia.

That’s the story so far. At the moment he’s more interested in Liverpool beating AC Milan in the Champions’ League on 25th May. I hope you’ll all be rooting for them.
The development of the Down syndrome phenotype

Mandy Wood

The Down Syndrome Educational Trust, Portsmouth, UK

In the first of these new features, Mandy summarises a discussion between the Trust’s practitioners, which focused on a new research paper by Deborah Fidler entitled ‘The emerging Down syndrome behavioural phenotype in early childhood’.¹

This month’s practitioners meeting involved an interesting and fruitful discussion of a new paper published in *Infants and Children*. The author, Deborah Fidler, of Colorado State University has been working in the field of genetic syndromes associated with intellectual disabilities, including Down syndrome since 1997. This paper clearly and concisely reviews the growing body of research into the already well-established concept of the behavioural phenotype associated with Down syndrome.²³

However, the major focus of the paper is to examine the profile from a developmental perspective, i.e. whether the so-called ‘typical’ (and some might say ‘inevitable’) profile presented by the majority of individuals in childhood and adolescence is already present and/or becoming established in infancy. She frames this question within the context of early intervention, highlighting the necessity of creating a curriculum and style of delivery, which is grounded in scientific research evidence regarding children with the specific diagnosis of Down syndrome and not a programme that simply fits a wider target audience of children with developmental delay.

This review does not aim to describe the typical profile as Sue Buckley reviewed this very clearly in her article ‘Specificity in Down syndrome’ in the last issue.⁴ Instead, the aim is to draw out the conclusions of Deborah’s paper with regard to the development across time of the phenotype and some of the implications of this for early intervention and school support.

What is a ‘phenotype’?

The term phenotype describes sets of observable traits, as determined by both genetic makeup and environmental influences. Deborah explains that phenotypes are ‘probabilistic’.⁵ This means that people who have Down syndrome are more likely to share one or more characteristic specific behaviours, as opposed to those with a general developmental delay. Secondly, not every child with Down syndrome will show all the behaviours and thirdly some of the behaviours associated with Down syndrome may appear in other syndromes. Phenotypes are purely descriptions of characteristics, which often appear together as a syndrome. The phenotype does

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Key points in Deborah’s article

- Research supports an emerging Down syndrome phenotype:
  - visual and social functioning and self help and daily living skills are relative strengths
  - speech and language, verbal processing and motor functioning are relative weaknesses
  - Certain aspects of this phenotype are apparent in infancy although the differences between the skills areas are much smaller than in older children
  - The discrepancies between skill areas may be magnified as the children age and develop
  - Intervention in infancy may be able to prevent or offset the developmental trajectory associated with Down syndrome
  - Intervention which is grounded in scientific research into the phenotype and utilises the children’s strengths is likely to be most effective

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http://www.down-syndrome.info/library/periodicals/dsnu/04/04/
not explain why these traits appear together or how they might interact. The development of the phenotype

Deborah indicates that from her own research using the Mullen Scales of Early Learning that a typical profile of “relative strengths in visual processing and receptive language and relative weaknesses in gross motor skills and expressive language skills” appears to be emerging by the age of 2. Further data from parent reports showed the toddlers to have strengths in socialisation skills but weaknesses in communication and motor skills.[6,94] Interested readers are referred to her original paper to explore the specific details of each domain of functioning as Deborah highlights many pieces of research which show that sweeping generalisations about strengths and weakness are not always useful as there are many subtle nuances within these areas, i.e. when more specific skill areas are examined, one begins to see that not every skill within a domain is always a strength or a weakness. For example, within visuo-spatial processing (generally discussed as ‘a strength’), although visual imitation and visual memory skills do seem to be strengths, spatial and visuo-construction skills appear to be relatively weaker.[5,88] There are also aspects of social communication, which are weaker than others, e.g. non-verbal requesting (using gestures like pointing to ‘ask’ for something) is a relative weakness whereas social interaction and engagement skills are often seen as a strength.[pp.90–91] Again, in the field of motor functioning, running and agility are actually sometimes on a par with typical development whereas other motor skills such as motor planning and certain precise movements of limbs and fingers are more delayed.[pp.91–92]

Through the looking glass: Tiny variations and huge gulfs

Another very important point, which Deborah describes, is that although the typical profile does appear to be present in an embryonic form during infancy, the discrepancies between areas of strength and areas of weakness are much smaller than they appear to be in older children. She suggests that these “tiny variations” may become “magnified” as the children mature and “snowball” into the distinct profile with which many readers will be familiar. The implication is that certain interventions, at so-called sensitive periods during development may help to “prevent or off-set” this process.[9,97]

The concept of critical and sensitive periods is a controversial one in the research literature, not least due to the fact that the term ‘critical’ implies that once a certain window of opportunity has passed, one can never acquire a skill with the same degree of competency. However, it is likely that there may be times when the brain is more receptive to certain types of learning. It is likely that there is, for example, a sensitive period for learning grammar and this is particularly salient for children with Down syndrome, for whom this appears to be a particular area of weakness.[4] This led the team to discuss the potential of early reading for developing children’s verbal short-term memory, syntactical knowledge and use of grammar in their expressive language. We discussed the fact that those children who had started reading activities early at the age of 2.5–3.5 years of age and had developed extensive sight vocabularies may have made better progress with regard to the effects on speech and language, particularly grammar development, than those who started later. Interested readers are referred to Reading and writing development for individuals with Down syndrome - An overview[6] for a discussion of these findings. This is, of course, not to say that targeted intervention at any age is ineffective, as many adolescents and adults with Down syndrome have demonstrated significant progress in a wide range of skill areas, including literacy, later in life.[19] The old adage ‘better late than never’ comes to mind even if ‘it’s never too late’ is not always quite the case.

Nature and nurture

An extremely important point raised by this article, which must be highlighted to every individual working or caring for a person with Down syndrome, is that a diagnosis of Down syndrome in early infancy does not predict the future in any certain way. Development is a dynamic process, whereby experiences within the environment are key to the way in which the brain itself develops and is organised.

The idea of a typical profile associated with Down syndrome is important to gain a general understanding of which styles of intervention may be helpful however, each individual with Down syndrome will only share the typical traits to a greater or lesser extent, some may share characteristic of other syndromes, some may have a full diagnosis of another syndrome, as Sue Buckley describes in her article on dual diagnosis, see p. 114 of this issue. As we shall see in the section on implications, below, this point is crucial with regard to the ways in which parents and professionals interact with the children as no single approach will be equally effective for every individual with Down syndrome.

Early intervention

Above it was noted that intervention in infancy may help to prevent or offset the emergence of some of the key weaknesses associated with

References

Down syndrome in childhood and beyond. However, Deborah indicates that this can only happen under certain circumstances, possibly the most potent of these being the importance of tailoring the intervention to the emergent profile of strengths and weaknesses presented in infancy.[6 94]

Ideally, intervention should start as early as possible and should always involve parents and children. Also, it is likely that parents who understand the rationale behind different aspects of the intervention will be more successful in their targeted work at home. Therefore, some degree of overt training may be necessary as well as modeling practical activities and games to the parents. The activities are likely to be most effective when they build on the children’s visual and social strengths and are tailored to the individual likes and dislikes of the individual children. One way in which this idea can be applied is by embedding opportunities to display skills which are likely to be more difficult for the child (e.g. speech sound production or precise fine motor movements) within tasks that will be perceived by the child as ‘do-able’ and fun. For example, action songs or pretend play scenarios, which are often extremely popular, could be used as a context in which to practice particular speech sounds.

Also, it is important to collect information from families about activities, toys, topics and so on which will be particularly motivating to each individual child so that these can be incorporated into activities to target specific skills and as reinforcements (rewards). One can begin to see from this discussion that for early intervention for children with Down syndrome to be most effective, a collaborative approach between practitioners and parents is essential.

**Personality and motivation**

Deborah also draws the reader’s attention to research on personality and motivation, which indicates that many children with Down syndrome share certain qualities, which manifest themselves in a characteristic style of social interaction.[89-92] Although the literature on temperament in infancy suggests that infants with Down syndrome show the same distribution of temperaments as typically developing infants, by childhood there seems to be a tendency to show decreased task persistence and variable motivation during work-related situations. Many children can be seen to utilise their strong social skills to engage others in ‘diversions’ and collude with them in a variety of behaviours unrelated to the learning task. She also cites research that indicates that children with Down syndrome tend to make more efforts to elicit help from adults than to persist with a task and develop their independence and problem solving skills and a study, which suggests that children with Down syndrome are less likely to repeat previous successful outcomes.[9 93] These observations may be helpful in developing guidelines to help those who support and particularly are involved with testing and assessment of infants and children with Down syndrome.

However, it was noted above that children with Down syndrome show enormous individual variation. As practitioners, an understanding of the behavioural phenotype is extremely useful for those working with infants and children with Down syndrome at one level, (e.g. curriculum planning) but on an individual level, it is also crucial to take a step back from the profile and simply observe the subtlety of the behaviours displayed by the child and the exact situations in which they occur.

**Conclusion**

This paper provided an interesting starting point for a discussion, which helped us to reflect on our practice with children and families both in early intervention and school liaison. It also provided ideas for future publishing and training activities and inspired us to think about potential research questions for the future.

We would encourage parents and practitioners to read the full article which has in-depth discussion of issues relevant to early intervention for all aspects of development and can be found at http://depts.washington.edu/isei/review/yyc.html.

The Trust practitioner and research team look forward to sharing Deborah’s work with her further at the 4th International Conference on Developmental Issues in Down Syndrome, to be held in Portsmouth, in the UK, in September, 2005. Please see page 159 for more details of this forthcoming conference. The full programme is also now available on our website, http://www.downsed.org

**References**

Research

We are keen to support postgraduate research into issues relating to Down syndrome and this section of Down Syndrome News and Update often includes adverts from researchers who are currently recruiting participants. Readers should note however, that the Trust are not usually involved in any way with these projects and therefore with have no further information about them.

In a future issue of Down Syndrome News and Update we are hoping to publish a short article about the advantages and disadvantages of participating in research projects. This will include information that families should consider when deciding whether or not to participate and make suggestions about questions to ask the researchers before making a decision. It will also give information about the ethical guidelines that have to be upheld by those completing research with children and families.

Language Research Project – help needed

The psychologists at The Down Syndrome Educational Trust and the Child Development Group, Psychology Department, University of Reading are collaborating to look at early language development in children with Down syndrome, children with autism and typically developing children.

We need parents willing to complete a straightforward checklist of the words and signs that their child understands and/or uses. If you have a child with Down syndrome between 2 years and 8 years of age and would be willing to help with this, please contact me on 02392 893885 or at sue.buckley@downsed.org. I will then mail you the questionnaire and stamped return envelope.

The findings will be very helpful in adding to our knowledge of the rates and variability of progress in children with Down syndrome as well as contributing to the Reading research project.

We will send the results to everyone who takes part.

Professor Sue Buckley, Director for Research
The Down Syndrome Educational Trust

Early Support

Information for parents – Down Syndrome

The staff of The Down Syndrome Educational Trust and the Down’s Syndrome Association have been working together with the Early Support team to produce an information booklet which will be given to every new family with a baby with Down syndrome in the UK. The booklet will be available from mid-July and you can order a copy by going to the website at www.earlysupport.org.uk

We would like to thank the many families who have worked with us and read two drafts as the booklet progressed. It is quite a detailed booklet and we appreciate the time given by everyone who read it and sent back comments. They were all noted and the final text reflects parents’ views.

This booklet is part of a programme of work funded by the UK government and aimed at improving services to families for the first three years of a baby’s life. We are all working on more materials to support early intervention services, including a Developmental Record for Children with Down syndrome for families, which will be described at our September Conference and available spring 2006.

You can read more about the whole Early Support programme, which firmly believes in putting control in the hands of families and in developing flexible and effective support services, on the website. Family Support packs can be obtained from the website and, if you live in the UK, you might ask if key-worker services are being implemented in your area yet. Each family should have a key-worker to help them to decide what they would like for their child and to co-ordinate early intervention and therapy. In some areas, this is being called ‘The team around the child’ approach. For all our readers from other countries, all the materials are available for download from the website. This is an exciting initiative and is certainly having an impact on services to families in the UK.

http://www.earlysupport.org.uk
Requests for participants

What works for us: Parental perspectives and Early Intervention

Alice Paige-Smith and Jonty Rix

There is currently a great deal of emphasis on children with Down syndrome and their parents becoming involved in Early Intervention programmes. These interventions can involve all kinds of professionals and activities and can be supported by many different kinds of advice. Much of this Early Intervention involves parents carrying out specific tasks with their children, other activities are built into a play situation, some involve professionals and require little parental involvement.

This piece of research wishes to find out what approach parents feel best suits them, their child and their situation. The first stage of the research project has considered the types of provision and early intervention experiences that parents have had with their children. Subsequently, we would like to focus on parents views - how you think your child learns in the home context. It is intended that this should operate as a pilot study for a wider research project into parental perspectives on Early Intervention.

The research is being conducted by Alice Paige-Smith and Jonty Rix from the Open University. Alice has considerable experience of presenting the parental viewpoint, while Jonty is a parent of a young boy with Down syndrome. The research would involve either a 30-60 minute face-to-face interview or a phone interview.

If you are interested, please get in touch by e-mail or phone:

Alice Paige-Smith 01908 858857
E-mail: a.g.paige-smith@open.ac.uk

Jonty Rix 01444 819210
E-mail: j.r.m.rix@open.ac.uk

Exploring learning through listening

Much of schooling involves learning through listening to teachers and it is important that they are able to recognize the diversity of pupils’ needs and adapt their speech accordingly. I know from my experience as a teacher that this is not an easy task. My research project therefore aims to provide classroom teachers with a better understanding of what speech rate is most appropriate to use in the classroom to help improve the education of children with Down syndrome ages 5-11.

The project has 3 stages:

1) The initial stage will involve collecting information through observation and assessment to establish the learning profile of each child with Down syndrome. The results will then be used to decide which story is best suited to each child in the later listening tasks.

2) The second stage will involve presenting the stories at slightly different speech rates and seeing what pupils can remember.

3) For the final stage, the results will be analysed to establish the optimum speech rate to help the children. Staff in the pupils’ class will then be asked to try and adopt that speech rate during some lessons. The interaction between teachers and children will be observed and this will be followed up by interviews with the class teachers.

In order to make this research worthwhile I need to find a broad sample of children with Down syndrome. I would therefore be most grateful if you would be willing to allow your child to join this project. If you are prepared to allow your child to help with this research, please contact me by ‘phone, letter, fax or e-mail. Thank you very much.

Jin-Chang Huang

Contact details:
Mr. Jin-Chang Huang, Research Student, Department of Education, University of Bath, Bath, BA2 7AY.

Mobile phone: 07775 99 49 69, Fax: 01225 386113,
E-mail: JCH27@bath.ac.uk

The project is supervised by Dr Jill Porter 01225 386857
Right to Know About … Friendships, Sexuality, Personal Safety

Vicki Brown, Anne Squire, Lorraine Forrest, Annette Fewings, Jill Phillips, Lynda Lovell, Judy Opolski and Deborah Marlin

The Down Syndrome Society of South Australia Inc.

Reviewed by Mandy Wood
Psychologist, The Down Syndrome Educational Trust

The program aims to help students with Down syndrome “to develop a range of skills and knowledge that will help them to make and maintain friendships, express their sexuality in appropriate ways and live safely in the community”. It comprises four main sections: About the Program and Modules One, Two and Three, on friendship, sexuality and personal safety respectively. This review will examine each of these sections in turn following a more general description of the complete package.

First impressions
Initially, two things impressed me; firstly, how the clear and colourful layout helps the user to navigate one’s way through the program and secondly, having explored the options for just a few minutes, I was impressed by the sheer breadth of the information already completed, with more still to come. As I became more engrossed in the ‘mechanics’ of how the program operates, I was impressed by the attention to detail, the tight structure and the overt application of sound educational and psychological principles. The planning section epitomises this with its thorough approach covering “special considerations” such as reporting of abuse, working in private, informing parents and obtaining consent, how and when to review progress and a “troubleshooting” section. The latter is an excellent addition, which should help teachers and assistants to ‘be prepared’ to react quickly and appropriately should certain issues arise through the teaching.

The foreword by Professor Roy Brown, editor of The Down Syndrome Issues and Information Adult Series (see p.147 for more information) highlights two “challenges” for families and professionals working with individuals with Down syndrome; firstly, the wide range of abilities and experiences found amongst people with Down syndrome and secondly the perceptions and actions of others towards people with Down syndrome. In terms of an effective teaching resource, Roy’s first challenge implies that the resource will need to be flexible and include strategies for differentiation. The second challenge suggests that other people’s perceptions of the needs of people with Down syndrome may affect the way in which sexuality and relationships education is approached by parents and professionals and whether a program such as Right to Know is accessed at all in some cases. The Right to Know program tackles these key issues very successfully.

Differentiation
In my introduction, I suggested that many people may see this program as a ‘gift’ as it is a highly structured and detailed, developmental program which matches the design of teaching activities as accurately as possible to the specific profile associated with Down syndrome. However,
as with any ‘off-the-shelf’ curriculum, especially one matched to the needs of a specific group of learners, it could be easy to slip into a rather automated and unreflective mode of delivery - the program is very clear that this is not the way to proceed! The authors underline throughout the text, that users must work collaboratively with the student and his or her family and significant others to adapt the teaching to their individual physical, intellectual, emotional, social and cultural needs. Suggestions are made about how to modify or extend activities to meet the wide variety of abilities, needs and experiences throughout the activities and the introductions and rationales clearly explain why this is essential, particularly in a program designed to address the very sensitive topics of personal, social and sexual development.

Raising awareness

Roy also implies that in some cases the greatest restrictions on the development of people with Down syndrome are the attitudes of others, including parents and professionals. Through the well-referenced and clear introductions and rationales, the Right to Know package provides an excellent source of information for informing and educating parents and professionals. This is not just a program that will help people with Down syndrome to improve their quality of life, it is a program which will educate and inform everyone involved with caring for and supporting the development of people with Down syndrome. To this end, the introduction, rationales and teacher survival guide could be used as part of the training provided to teachers, learning support assistants, support workers and so on. The program should certainly provide a great source of support and information to parents, education, health and social care professionals.

About the program

The program is introduced in the section called “About this Program” and it is here that the reader is introduced to the ‘Right to Know continuum’, a diagram which clearly depicts the content of the program and the suggested ages at which the authors intend units to be delivered (Figure 1). The program can be delivered as entire developmental program starting in early childhood or as discrete units or sessions at an individual or small group level.

Each module comprises a series of units which include detailed rationales of the content and style of delivery, overviews of relevant research, aims and objectives, information sheets for parents and schools, further notes and resources and session-by-session planning detailing key objectives, teaching points, equipment and activities.

Units contain numerous attractive and colourful worksheets, which often make up short booklets about key concepts for the student to ‘revisit’ at home and school. This technique is likely to help the student to transfer new vocabulary to his or her spoken language in a similar way to the conversation diary, which has been described in our various publications [1,4-6]. The worksheets make use of a variety of techniques which allow the student to record his or her work with the

![Figure 1. The ‘Right to Know continuum’](image-url)
of experts who fully acknowledge aspects of this profile in each activity that they present. For example, session planning builds in systematic opportunities for reinforcement of previously taught skills and knowledge through repetition and practice. Sessions are carefully planned to utilise teaching methods, which meet the children’s specific profile of needs and these are detailed in the section called ‘instructional techniques’. On the whole, the activities tend to minimise recording through written work, which is an advantage as the primary goal of the activities is not to develop literacy skills however, the program could be improved by building in and signposting more opportunities for key skills development in speech, language, literacy and numeracy, e.g. providing target vocabulary to be taught in each unit for comprehension and/or expression and reading at the beginning of each unit.

This is not just a program that will help people with Down syndrome to improve their quality of life, it is a program which will educate and inform everyone involved with caring for and supporting the development of people with Down syndrome.

Understanding the student with Down syndrome

The package includes a detailed section entitled “Understanding the student with Down syndrome” including sections on medical and physical issues, speech and language issues, specific learning difficulties, cognitive development, learning styles and individual and family considerations. Deborah Fidler’s recent research article (reviewed on p.135) discusses the development of the “behavioural phenotype” or typical profile associated with Down syndrome and one of the key strengths of this program is that it has been tailored very carefully by a team of experts who fully acknowledge aspects of this profile in each activity that they present. For example, session planning builds in systematic opportunities for reinforcement of previously taught skills and knowledge through repetition and practice. Sessions are carefully planned to utilise teaching methods, which meet the children’s specific profile of needs and these are detailed in the section called ‘instructional techniques’. On the whole, the activities tend to minimise recording through written work, which is an advantage as the primary goal of the activities is not to develop literacy skills however, the program could be improved by building in and signposting more opportunities for key skills development in speech, language, literacy and numeracy, e.g. providing target vocabulary to be taught in each unit for comprehension and/or expression and reading at the beginning of each unit.

Understanding the student with Down syndrome presents relatively detailed information on the specific profile and how this affects the students’ learning style and differentiation needs. From the inclusion of this level of detail one can infer the authors feel that it is essential for people supporting the learning of people with Down syndrome, to really understand the profile of needs.

The flow of the text is somewhat staccato, in that it comprises a series of quotes from a variety of well-known authors in the specific fields of health, speech and language, motor and cognitive development (e.g. Siegfried Pueschel, Jon Miller, Libby Kumin, Robin Chapman, Sue Buckley, Jennifer Wishart) without a great deal of additional description to hold the work together. However, this does not detract from what is, in total, a helpful overview of current thinking based on up-to-date scientific research. Each section concludes with a useful table summarising the key problem areas, implications and strategies for optimising teaching and learning.

I feel that this section somewhat overplays the weaknesses of the student with Down syndrome, making them feel a little ‘too special’. This contrasted with important point made in the Teacher’s Survival Guide (included with Module 1) which warned against “too special syndrome” (p.14) a trap into which teaching and support staff can fall when they concentrate on the child’s “special considerations” to the exclusion of “normal expectations”. Although this section did indicate that the children show “great skill in imitating actions and gestures of others” (p.35) this was not linked to the children’s tendency to display better social behaviour than children with similar levels of learning disability without Down syndrome. Also, the authors emphasise visual processing as a strength in comparison with the ability to process spoken information, however, they do not link this strength to the ability of many children with Down syndrome to develop an extensive sight vocabulary for example.

This section included a great deal of detail about limitations of the students with Down syndrome and maybe more could have been said about strengths.

Due to this imbalance the language felt slightly negative and some generalisations were made which may not be appropriate to all children with Down syndrome, e.g. “Students will be unable to process higher order questions e.g. how, why, when. Avoid using ‘how’, ‘why’ and ‘when’ questions” (p.46). In this...
example, this is not always the case and many older children and adolescents may be targeting higher order questions as part of their speech and language therapy work. The authors also suggest that “information is gained using one sense at a time”, that “students will focus on information received through the visual sense to the exclusion of other senses” and that “students will not learn new skills/material by only verbal instruction”. These points are made rather dramatically and there is no research evidence to suggest that they are strictly true, or apply equally to all children with Down syndrome. However, it is commonly accepted that children with Down syndrome learn best when new learning is supported with visual aids such as pictures, photographs, printed words to support their understanding of the spoken word.

Overall this is an important and helpful section but the learning strategies that may be used to overcome weaknesses could also be expressed more positively, e.g. students with Down syndrome learn best when...

**Module I: Friendship**

This module aims to enable the student to develop and build upon social interaction skills from early childhood through to adolescence. It aims to develop an understanding of self, the ability to recognise, name and manage common feelings, to meet social expectations for grooming and self-presentation, to use personal space appropriately and participate in relationships. Unit 1 centres on the production of an ‘About Me’ book which can be shared with peers, new teachers and other professionals. This is a great strategy as the book provides a reference point to help initiate conversation; it provides a series of talking points to help maintain the dialogue once started and unfamiliar children and adults will be supported if they find it difficult to understand the child (due to articulation difficulties) as the book provides information to support the conversation.

The booklet includes some worksheets, which introduce the concept of Down syndrome, which is a central aspect of the child’s developing self-concept. Unfortunately, the module and unit rationales say very little about self-awareness and self-knowledge about having Down syndrome and how this might affect one’s self esteem, behaviour and relationships with others. This is an interesting area and one which many parents, teachers and support assistants would probably have liked to know more about.

In Unit 3 on personal space, students are taught to develop their self-direction skills (“I stand an arm’s length and a step away”) in order to check how close they are when sitting and standing next to other people. The planning in this unit provides a good example of the way in which opportunities for practice and repetition have been carefully built into each session. Unit 4 on personal grooming includes activities to teach self-help skills such as face wiping, nose blowing, toileting and washing and drying the body. Unit 5 on emotions introduces vocabulary for describing feelings and teaches children a variety of words for different emotions, (e.g. a worksheet to teach a variety of words for happy including glad, merry, pleased, cheerful, jolly, content). This was a valuable aspect of this unit and it was felt that other units could have included a list of target vocabulary to be taught explicitly during the unit. The unit also targets children’s ability to recognise facial expressions for different emotions using pictures. Finding ‘good’ picture references for emotions work is often difficult – this program uses clip art images and the images are not always easy to identify. Recent research by Jennifer Wishart, Katie Williams and Tom Pitcarrn at Edinburgh University suggests that recognising facial expressions may be a specific area of difficulty for children with Down syndrome and so this is an area where it is important to try and use the best possible picture resources.[1] For this reason, it may be useful for students and assistants to create their own emotions picture references by taking photographs of the child, their friends and members of their own family pulling appropriate faces. The authors suggest that this may be appropriate for some students in the teaching points. Unit 7, which is targeted at older children and teenagers, introduces more advanced emotion words such as frustrated, anxious and harassment.

**Friendships – Teachers Survival Guide (Part 1)**

This guidebook recognises the necessity of developing strategies for social inclusion and “providing adequate staff time and resources to support programming to promote friendships”.[5] Although social development and social interaction skills are commonly acknowledged as a strength for most children and teenagers with Down syndrome, it does not follow that they will automatically have the skills to establish and maintain friendships. This handbook provides information about development of friendships in typical development, factors which might affect the development of friendships for children with Down syndrome and a host of strategies to use in school to support social inclusion and avoid isolation.

Once again, the booklet uses the characteristic clear and thorough style that runs throughout the program to describe aspects of the typical profile which may impact on social interaction skills and in turn the ability to integrate with peers, engage in conversations and develop ongoing friendships. It lists examples and strategies for combating problems. It is not possible to overstate the usefulness of this booklet as it really does provide an invaluable source of advice that will surely be welcomed by classroom practitioners across the globe.

**Module 2: Sexuality**

The second module provides a series of units which focus on sexual development, sexual norms of the
community, safe sex practices and appropriate sexual expression. Most of the units are intended for delivery in middle childhood (9-13) and the senior years (14-18) although the first unit on body parts is targeted at younger children (5-8 year olds). At present only the first four units, covering anatomy and puberty, are available.

Unit 1 and 2 focus on teaching key vocabulary for talking about the body. Vocabulary checklists are provided at the start of the units with ideas on how to measure the child's current comprehension of body related words. Several columns are provided so that understanding can be compared over time. This takes into account the important point that children with Down syndrome often perform to different standards at different test sessions and therefore it is important not to make judgements based on single assessment sessions. The units provide opportunities to learn new vocabulary about public and private parts of the body, places where it is appropriate to get dressed and undressed and appropriate and inappropriate touch.

Units 3 and 4 focus on puberty for girls and boys respectively and are intended to be delivered to single sex groups. Learning about puberty for the opposite sex comes later in the program and this unit is yet to be published. The advantage of this is that only the most relevant information is presented at one time. This means the student is not confused by information about bodily changes which will not happen to them until they have ‘got to grips’ with their own development. The units provide information about how to work collaboratively with families to ensure that the work is understood and reinforced at home and that family, religious and cultural beliefs are taken into consideration. The introduction to unit 3 (for girls) provides a helpful summary of advice from ‘real parents’ about managing menstruation. Glossaries of key vocabulary with simple definitions of key vocabulary are also provided. The materials for managing menstruation are excellent, e.g. a visual timetable for changing sanitary pads, sentence strips to learn how to discreetly ask for ‘private help’ if necessary. The units both start with a review of private body parts and changes at puberty for each sex. The girls’ unit then focuses solely on menstruation while the boys unit targets the emotions of anger and embarrassment, erections and ‘wet dreams’. It is interesting to note that the authors have included activities on emotions in the boys unit but not in the corresponding girls unit (although the feelings of ‘moody’ and ‘in pain’ are covered in the section on pre-menstrual tension). There is no rationale for why anger and aggression have been targeted in the boys unit but not the girls and staff who have not had experience of pupils with Down syndrome may misinterpret the inclusion of these activities as meaning that adolescent boys with Down syndrome typically have significant problems with aggression.

The authors suggest that work completed in units 3 and 4 can be used to create a ‘book of life’. The book can be repeatedly read to provide opportunities for the student to reinforce previously learnt information, maintaining comprehension and improving expressive language. The book is intended to remain private and the unit provides ideas about how to make sure the student keeps their book private and shares it only with a nominated adult at home.

Module 3: Personal Safety

The final module targets skills and behaviours to help children and adolescents with Down syndrome to engage safely in community life. The sessions include activities to teach students to differentiate between ‘public’ and ‘private’ places and behaviours, respond differently to people they know or to strangers, safely use public places such as streets and public toilets, recognise situations in which they feel uncomfortable and tell a trusted adult and react assertively in threatening situations. The units are generally intended to be taught throughout middle childhood and into early...
adolescence. However, the rationale describes that opportunities for repetition and reinforcement are crucial for students to learn protective behaviours and therefore the unit content may need revisiting over and again throughout adolescence depending on the students’ needs.

The rationale to this unit provides a frank summary of the literature relating to sexual abuse of people with learning disabilities. Factors which make young people, especially young women, with Down syndrome more vulnerable to abuse and less likely to be believed if and when they do disclose abuse as described and this makes for chilling reading. It also describes how the teaching of social skills and assertiveness training can not only have the effect of protecting young people from others it can also decrease displays of inappropriate sexual behaviour from the individuals themselves.

Unit 2 uses an approach called ‘Circles’ which is commonly used in Australia to teach students about interpersonal boundaries. It can be used to help students to learn how to greet different categories of people and who to ignore. It can also be used to protect against inappropriate hugging. This is an issue which is raised frequently by parents and professionals. Sometimes parents have discussed that it is not in fact their sons and daughters who are inappropriately hugging others but that adults are hugging their children and reinforcing inappropriate touch, i.e. treating them as if they are younger than they are.

Unit 4 is a particularly interesting and well-planned unit, which helps students to develop assertiveness. Sentence strips are used to help children to practice ‘set phrases’ that they could use if they felt unsafe in a social situation. This is a good strategy for children who can read as daily practice with the sentences strips should help transfer the words and phrases to the children’s expressive language.

In many ways Unit 5 is probably the most important unit of the entire program as it teaches the child strategies to prevent abuse and how to report abuse should it occur. The aim of the first few sessions is to help the student to recognise how the body lets us know when something is wrong. This acknowledges that children may not be aware that they feel ‘unsafe’ or scared. It aims to teach them to be aware of signs such as a racing heart beat, needing to go to the toilet and having a tummy ache as warning signs that they are in a situation that they do not feel comfortable with. The unit also covers creating a ‘helping hand’ a visual device which should help the student to remember who they can talk to in an emergency and how to tell the difference between ‘good secrets’ and ‘bad secrets’.

Conclusion

The Down Syndrome Society South Australia must be very proud of this new resource and we look forward to tracking its use with children with Down syndrome at home in the UK and abroad. With such a detailed program, it will be interesting to see how teachers decide to integrate its use into the rest of the child’s curriculum. For example, will teachers choose to use the materials to differentiate the personal, social and health curriculum followed by the child’s mainstream peers or use the package as a discrete activity to be accessed at times when peers are working on something entirely different. Perhaps, staff will find the resource so useful that they will in fact ‘differentiate up’ and use it as a base for teaching the whole class! The package certainly will be useful for a wider range of children and young people than just individuals with Down syndrome.

The Right to Know Program will be available shortly from the Down Syndrome Educational Trust and staff from The Down Syndrome Society South Australia will be leading a workshop on using the Right to Know program at the 4th International Conference on Developmental Issues in Down syndrome, here in Portsmouth in September - see p.159 for more information.

References

New publications

Luke has Down’s syndrome

By Jillian Powell

Reviewed by Mandy Wood, Ben Sacks and Clare Tatterson

The Down Syndrome Educational Trust, UK

This colourful new children’s book from Evans Brothers Limited may be a useful resource to use with children with Down syndrome, their siblings and peers. Primary school teachers may find it a useful addition to the school library whether the school includes a child with Down syndrome or not.

The book shows Luke phoning his friend to arrange a trip to the adventure playground. We see Luke using public transport, at the playground, in a café, buying flowers using Makaton, walking his dog and playing with his friends at Cubs. The message in the book is that Luke shares many characteristics with children of his own age although there are some key differences relating to the need for “extra help with some things at home and at school”. One of the key strengths of this book is the way in which Luke is depicted as an active member of his community, included alongside his mainstream peers at Cubs and out and about with his typically developing friend Paul.

Key vocabulary from the text, (including Down syndrome, glue ear and Makaton signing) is briefly expanded upon in boxes and a glossary at the end of the book. The level of detail is very basic and the book could have benefited from being more informative about the implications of having Down syndrome.

In places, the text is rather negative in tone, for example “Dad usually reads to me before I go to sleep. I can only read a few words myself …”. This may be true for Luke, and it is his story that we are following in this book, however, a box drawing out the important point about the huge variability in abilities of children with Down syndrome would have helped to overcome this issue. There was also rather a heavy focus on what Luke needs help with, e.g. at the bus stop “someone has to tell me when to put out my hand to stop the bus”, in the café “Paul helps me count out the money to pay” and, getting ready for cubs “sometimes I need a bit of help getting dressed”. It may have helped to focus more positively on Luke’s growing independence and the self-help skills that he is developing.

Finally, there is a section on further information with some useful addresses, websites and additional children’s books.

While this book has some limitations, it is a colourful book, which is likely to be useful in stimulating further discussion with younger readers, with and without Down syndrome.

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First books in DSii Adult Living series now available

We are pleased to announce that the first books in the DSii Adult Living series are now available for purchase. These books are:

• Life for adults with Down syndrome - An overview [DSii-01-07]
• Information Communication Technology for adults with Down syndrome [DSii-16-11]
• Advocacy for adults with Down syndrome [DSii-22-10]
• Spiritual well-being for adults with Down syndrome [DSii-22-20]
• Drama and the arts for adults with Down syndrome - Benefits, options and resources [DSii-22-08]

Each of these books costs £5.90 plus postage and packing.

The other books in the series are currently under preparation, and we expect to publish them during the next 12-18 months. They will cover the following topics: transitions to work and education • drama and performing arts • reading, writing and numeracy • further and tertiary education • independent living • relationships • family issues • leisure and recreation • women’s issues • mental health and emotional well-being • the law in relation to adults with Down syndrome • international and cultural aspects of Down syndrome. Check our Web site at http://www.downsed.org/dsii-adult/ for updates.

About the DSii Adult Living series

Building on the success of the Education and Development series for children aged 0-16 years, the DSii Adult Living series covers the wide range of issues affecting the quality of life for adults with Down syndrome. The DSii Adult Living books are designed for families and professionals, specialists and non-specialists. Each book includes reviews of relevant research, backed up by case studies and practical examples. References for original research, supporting materials and further resources are also provided.

The books in the DSii Adult Living series are written by expert researchers and practitioners from around the world. Their advice and information is based on the latest knowledge and years of practical experience of supporting adults with Down syndrome and other intellectual disabilities. The series is being edited by Professor Roy Brown – who is a leading expert in this area, and is Emeritus Professor at the University of Calgary, Canada and Flinders University in Australia, and is consultant and Research Director to the Down Syndrome Research Foundation in Canada.

The development of the DSii Adult Living series has been supported by the Freemasons’ Grand Charity, the Rufford Maurice Laing Foundation, the Marchday Charitable Trust, and Down Syndrome International.

Translations of Down Syndrome Issues and Information

The first part of the Spanish translation of the Development and Education series is published. The Spanish translation is being undertaken under the Editorship of Professor Juan Perera and ASNIMO, the pioneering Down Syndrome Association for the Balearic Islands based on Mallorca for the past 28 years. The Spanish Translations are being published by Ciencias de la Educación Preescolar y Especial, General Pardiñas, 95 - 28006 Madrid, Spain, and are packaged in topic packs.

The Spanish Speech and Language pack (ISBN: 84-7869-473-0) contains the research overview, the 3 practical books for work with children from birth to 16 years, and the 6 Speech, Language and Communication checklists. The rest of the Development and Education series will be available in Spanish during the coming months. For more details of how to purchase, e-mail: clientes@editorialcepe.es or see http://www.editorialcepe.es/

Norwegian translation of the books is also underway and the translation team has been led by Jarl Formo and colleagues at Sørlandet Kompetansesenter in Norway. These are being printed by The Down Syndrome Educational Trust in the UK and can be obtained from the Trust or from Songvaar Industrier, Linne-grøvan 13, 4640 Sagne, Norway (http://www.songvaar.no). Books translated so far are Accessing the Curriculum, Reading and Writing for Infants with Down Syndrome (0-5 years) and Reading and Writing for Children with Down Syndrome (5-11 years). Further translations are planned in the near future.

Contact Howard Hurd at the Trust (Howard.Hurd@downsed.org) if you are interested in arranging translations into another language.

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http://www.down-syndrome.info/library/periodicals/dsnu/04/04/
12 - 15 June 2005  
The 1st Asian-Pacific Regional Congress of IASSID. The Howard International Hotel, Taipei, Taiwan.  
http://www.asiapacificiassid.org/

5 July 2005  
UCE Perry Barr, UK. E-mail: trace.erving@southbirminghampct.nhs.uk.

4 - 15 July 2005  
Disability Discrimination Law Summer School, National University of Ireland, Galway, Ireland. See page 151.  
www.eusummerschool.info

7 - 10 July 2005  
‘Imagine’ - National Conference of the National Down Syndrome Society (NDSS)  
The Fairmont Hotel, Chicago, USA. www.ndss.org

29 - 31 July 2005  
National Convention of the National Down Syndrome Congress (NDSC)  
The Hyatt Regency Hotel, Anaheim, California, USA. www.ndscenter.org

15 - 18 September 2005  

29 September - 1 October 2005  
2nd Southern African Down Syndrome and Intellectual Disability Conference. Birchwood Hotel and Conference Centre, Johannesburg. E-mail: dssalara@icon.co.za www.downsyndrome.org.za. See page 149.

6 - 8 October 2005  
9th International Symposium of The Society for the Study of Behavioural Phenotypes.  
Novotel, Palm Cove Resort, Cairns, Australia. www.ssbp.co.uk. See page 149.

27 - 28 October 2005  
EDSA meeting in San Marino. Details to follow.

2 - 5 August 2006  
The 2nd International Congress of IASSID-Europe.  
University of Maastricht, Maastricht, the Netherlands.  
www.unimaas.nl/congresbureau or www.iassid.org/

22 - 27 August 2006  
9th World Down Syndrome Congress.  
Vancouver Convention and Exhibition Centre, Vancouver, BC, Canada. www.wdsc2006.com  
See page 149.
SOCIETY FOR THE STUDY OF BEHAVIOURAL PHENOTYPES
9th International Meeting

Treatment of Behavioural Problems in Neurodevelopmental Disorders

6th to 8th October 2005
Novotel Palm Cove Resort, Cairns, Australia

Keynote Speakers
Dan Donnai, University of Manchester, UK
Gillian Turner, University of Newcastle, Australia

The meeting will also include presentations on the treatment of:
Fragile X syndrome (Randi Hagerman, UC Davis, USA)
Prader-Willi syndrome (Leopold Curfs, Maastricht, The Netherlands)
Lesch-Nyhan syndrome (James Harris Johns Hopkins, USA)
Smith-Magenis syndrome (David Dossetor, Sydney, Australia)
Williams syndrome (Pat Howlin, London, UK)
FG Syndrome (John M. Opitz, Salt Lake City)

Register online at http://www.ssbp.co.uk/files/conference/society_index.htm or contact:
Robbie Fountain or Sue Hampton-Matthews
The SSBP Office, 2nd Floor, Douglas House, 1Bb Trumpington Road,
Cambridge, CB2 2AH, UK. Tel: +44 (0)1223 746100 Fax:+44 (0)1223 746122
E-mail: ssbprobbie@aol.com

important dates

Abstract submission to start September 2005
Abstract submission deadline February 6, 2006
Early registration deadline April 10, 2006

Please e-mail or check the website for further updates and details of Registration fees

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

European Down Syndrome Association news

The Disability Discrimination Summer School will be the first of its type in Europe to focus on anti-discrimination legal issues on the ground of disability. It will focus on the potential of the European Union Framework Directive on Employment in the context of disability. The Framework Directive is the single most important legal instrument at the European level combating discrimination on the ground of disability. Its success or failure will be crucial to the cause of advancing the rights of persons with disabilities in Europe.

This Summer School – which is conducted in partnership with Maastricht University and hosted by the National University of Ireland, Galway – will raise general legal awareness about the practical potential of the Directive in the disability context and should appeal to a wide range of persons and bodies including persons with disabilities, practising lawyers, judges, law students and disability NGOs as well as those more generally interested in public interest litigation.

More particularly, the Summer School is designed to impart skills as well as knowledge to enable participants to construct effective test case strategies under the Directive on behalf of persons with disabilities.

A prestigious teaching faculty has been assembled to deliver the programme. It is drawn from an international group of prominent legal experts and especially practitioners who have extensive experience in bringing test cases in the field of disability.

This Summer School is supported by the European Community Action Programme to combat discrimination (2001-2006). This Programme was established to support the effective implementation of new EU anti-discrimination legislation. This six-year Programme targets all stakeholders who can help shape in the development of appropriate and effective anti-discrimination legislation and policies, across the EU-25, EFTA and EU candidate countries. The Action Programme has three main objectives. These are:

1. To improve the understanding of issues related to discrimination,
2. To develop the capacity to tackle discrimination effectively and
3. To promote the values underlying the fight against discrimination.

For more information see: http://europa.eu.int/comm/employment_social/fundamental_rights/index_en.htm

The contents of this publication do not necessarily reflect the opinion or position of the European Commission Directorate-General Employment and Social Affairs. Neither the European Commission nor any person acting on its behalf is responsible for the use which might be made of the information in this publication.

Teaching Programme

The teaching programme runs for two weeks and is divided into four sections as follows:

Section I will identify the core challenges in making the EU Framework Employment Directive effective on the disability ground. It will set out the background to the Directive and parse in order to reveal the main interpretive challenges facing both domestic courts and the European Court of Justice (ECJ) on the disability ground.

Section II will take a sideward glance to reveal how these interpretive options have been confronted under international law (United Nations and the Council of Europe) and within cognate jurisdictions with a long history in the field (Canada, USA, UK, Ireland).

Section III will focus on the litigators’ perspective dealing with three key thematic issues under the Framework Employment Directive: Definitions, ‘Reasonable accom-
European Down Syndrome Association News

DISABILITY DISCRIMINATION SUMMER SCHOOL

Toward Effective Test Case Strategies


4 July - 15 July 2005

Robin Allen: Queen’s Counsel, is joint head of Cloisters, Barristers Chambers, London, U.K., with extensive litigation experience in the non-discrimination field.

Ellis Barry: Legal Adviser, Equality Authority, Dublin, Ireland.

Peter Blanck: Professor and Director of the Law, Health Policy and Disability Center at the Iowa College of Law and a disability rights litigator before the U.S. Supreme Court.

Jerome Bickenbach: Professor at Queens University, Canada and consultant to the World Health Organisation on the definition of disability.

Patricia Bregman: Canadian Lawyer, specialising in disability law and policy litigation.

Robert Burgdorf: Professor of Law at the University of the District of Columbia David A. Clarke School of Law and consultant to the U.S. National Disability Council.


Andrea Coomber: Legal Officer, Interights (International Centre for Legal Protection of Human Rights), U.K., with a special focus on strategic disability litigation.

Olivier De Schutter: Professor of Human Rights at the Catholic University of Louvain (Belgium) and a leading authority on the European Convention on Human Rights and disability.

Caroline Gooding: Special Adviser and Director of the Disability Rights Commission, U.K.

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Website: http://www.eusummerschool.info

Next meeting

The next meeting of EDSA will take place during the scientific conference being held in San Marino Italy from 27th-28th October, 2005.

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EDSA news

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Cultural, religious and political factors in developing services in Asian countries for people with disabilities

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Introduction

Disability is estimated to be more prevalent in the developing countries. It has been estimated by the UN that approximately two-thirds of the world’s disabled people live in developing countries.¹¹ This would indicate that people with disabilities are by no means an insignificant minority.¹² Yet it appears that services for people with disabilities such as Down syndrome are not equitably distributed throughout Asian countries.¹³ Why is this?

Factors in developing services

What factors then, influence the development of services for people with disabilities including individuals with Down syndrome? The obvious ones are demographic and related to issues such as environmental isolation. Generally, in developing countries infrastructure is very poor or non-existent. Many disabled people living in villages and remote areas are completely unaware that they can get help.⁴¹ Compounding all the demographic and environmental access issues are attitudinal barriers relating to disability in many parts of the region resulting from negative stereotypes and paternalistic assumptions about people with disabilities and their needs.³¹ Such attitudinal barriers, in various local manifestations, are a powerful and silent handicapping force. That force relegates people with disabilities such as Down syndrome to low priority in resource allocation and implementation action.³¹

South Asia has a long historical heritage of informal and semi-formal responses by communities and individuals to disablement from antiquity to the present. The present situation is almost certainly rooted deeply in the cultural heritage from the past.⁵¹

In many societies in developing countries a system of caring for persons with disability did exist but became dormant over an extended period of time. A typical example that can be cited is the care of persons with disabilities within the joint family system as well as through religious outreach.⁶¹ In Indonesia for example, Islamic organisations provide facilities for the care and training of people with disabilities.

Culture and religion

Myths and stereotypes surround disability (including Down syndrome) in many cultures. The myths and stereotypes are based on ignorance of disability and its causes. In the developing world, many people with disabilities – mental, physical or emotional – are hidden away by their families.⁶¹ Communities may blame a family for the presence of a disabled member, inferring that someone must have sinned and offended God.⁵¹

Not all religions see disability as a punishment from God. One of the basic principles of Islam is to believe in the wisdom of Allah in what He creates and commands, and in what He wills and decrees, in the sense that He does not create anything in vain and He does not decree anything in
which there is not some benefit. So, everything and everyone (including people with disabilities) exist according to His will and decree.

The Buddha taught that life is neither fair nor unfair and that there are absolutely no "shoulds." Why should an individual have become disabled? Well, why not? Thinking that life should be fair, judging that certain things should or shouldn't happen, are the causes of suffering.

The Buddha proposed the law that for every action there is a reaction. Applying it not to physical actions but to human actions. He called the law of human actions and reactions Karma, saying that "every object and occurrence in the universe is interconnected." No one can be said to exist independently. Karma means that because no event, no person, no thing is independent, everything we do can affect everything else in the universe and these effects will someday circle back to affect us.

Is disability a Karmic punishment? Some Buddhists believe in reincarnation and say that what happens to you in this life results from the circling back of your own actions from previous lives. Does this mean that being born with Down syndrome or getting polio as an infant is punishment for "bad karma" in past lives? Some believe disability is a result of something done (or not done), or because of something that wasn't handled properly, in a past life and now get another chance to 'do it right.' They don't think of it as a punishment.

Buddhists say that when we accept that everything animate and inanimate is "already broken," a physical disability – even a terminal illness – loses its abnormality. Actually, anything that is not broken, not "disabled," is really abnormal.

Anecdotal evidence indicates there is a lack of awareness and a lot of misinformation about disability, including Down syndrome, even among educated people. A paternalistic attitude exists towards many disabled individuals. Personal experiences indicate that many parents see their disabled children who are young adults as children unable to make decisions for themselves. They do not believe they are capable of a more independent life style and are not given opportunities to develop independence. Observations indicate that they do not have any ambitions for family members who are disabled. This appears to be the case especially where they can afford to enroll students in programs aiming to teach vocational and life skills. There appears to be little effort to involve disabled family members in family businesses and families seem to prefer to keep them hidden away if not at home then in programs that are not necessarily meeting their needs. Certainly opportunities to actively participate in the community seem rare.

Public attitudes often mean that disabled people are ridiculed if seen out in public. Personal experiences in Indonesia of taking students with disabilities (including Down syndrome) into the community have not always reflected this. Mostly people have been very helpful and accepting if somewhat surprised to see a group of disabled children and youths doing what their non-disabled peers do. However, parents have related incidents where their children have been the victims of ridicule or taken advantage of.

In Indonesia, there are special schools for students with disabilities. However, anecdotal evidence indicates that they do not work towards meeting individual needs. Curriculum are developed for specific disabilities but these tend to have a "one size fits all" approach to teaching children with disabilities. Class sizes are large and teachers are often ill-equipped to adapt programs to individual needs or to manage behaviours or appropriate learning experiences for students with disabilities. In many cases, untrained teachers or therapists are able to open centres claiming to be able to provide programs to help disabled children. They have inadequate or no qualifications and yet claim to be able to meet the needs of individuals.

Students with disabilities and Down syndrome are rarely found in mainstream classes in Indonesia. The segregation of non-disabled students from everyday contact with peers who have disabilities deprives both of the opportunity for mutual learning. Such learning being necessary to break down barriers created by ignorance, cultural stereotypes and myths and which hinder the provision of appropriate services to people with disabilities.

The lack of barrier-free access to numerous programs for the emotional growth, as well as cognitive and skills development of children and youth creates two classes among them – the "non-disabled" who participate and the "disabled" who are excluded. For adults with disabilities, the same lack of access to functional literacy and skills development programs means that very few can avail themselves of existing opportunities for self-improvement open to their non-disabled peers. Such opportunities being necessary if disabled individuals are to have any say in provision of services.

If there are any opportunities for education, it is usually disabled boys who receive them, and then it is usually through special church or charity run schools operated for disabled children, usually blind or deaf schools.

While public attitudes regarding the value of educating and training women have changed considerably throughout the Asia Pacific region, little has changed in this respect for women with disabilities. Girls with disabilities are often kept at home to do housework. The opportunity for them to receive an education or to
Disabled persons in general and poor disabled girls in particular are often not provided with or have little access to early intervention or rehabilitation services. The prejudice surrounding their ability and value continues to perpetuate the view that rehabilitating them is futile. Rehabilitation services in the developing countries of the region are generally still inadequate and poorly coordinated.\(^3\), \(^6\), \(^8\)

Disability creates and exacerbates poverty not just for the disabled but the entire family. Strong links between poverty and disability result in people with disabilities being one of the poorest and most marginalised sectors of the population. Women with disabilities are particularly vulnerable.\(^3\) They suffer from malnutrition and hunger, and they also lack adequate health services including maternity and trauma services.\(^3\)

Disability reinforces poverty. Exclusion and marginalisation of disabled people reduce their opportunities to contribute productively to the household and the community and thus increase the risk of poverty.\(^3\)

Inadequate education and employment opportunities, “internalized oppression” (a kind of psychological warfare), stereotypes borrowed from medieval English literature, the charity model and the lack of a cohesive movement and a united voice, have collectively ensured disabled people stay at the “bottom of the barrel”.\(^2\) The attitude that “poverty cannot be helped; it’s the developing countries’ fate, “kismet”, or lot, to remain poor” is not helpful in ensuring disabled individuals get a fair go. As the rich get richer and the poor become poorer, disabled people will remain the biggest sufferers for reasons not difficult to understand.

Inadequate education and employment opportunities for disabled people are two more reasons why people with disabilities have low status in a developing society. Some schools simply refuse to accept disabled children on the plea that “they will have a bad influence on the non-disabled students!”

As a result of such attitudes and unequal opportunities, many disabled children are forced to seek vocational training in trades like dress-making, book-binding, basket- and chair-weaving, etc. without completing even their primary education. Although this gives them a measure of self-esteem by affording them a chance to earn some money and not be a “burden on society,” their lack of education and lowly jobs ensures their status, and therefore, self-image, will remain poor. In some cases, parents also hesitate to invest in their disabled children’s education thinking it’s a bad investment.

Policy concern aimed at addressing the education and vocational training needs of all children and youth with disabilities is quite new in most developing countries of the region.\(^2\) Concepts of integration or inclusion are new to many countries and education about the benefits of such educational practices and philosophies for all needs to be wide reaching so all members of the community are given opportunities to learn.

Government and non-government organisations are working to provide services to disabled groups. It is recognised that there is a need to consult disabled people in provision of services and that they do not want to be passive recipients of services which may or may not be what they need. This highlights the need for education if disabled people are to be able to indicate what they want and need. This, however, will not happen unless disabled people (including people with Down syndrome) are empowered to make decisions for themselves. Paternalistic attitudes and ignorance will not result in provision of appropriate services for people with disabilities that will allow them to reach their potential. Attitudes to empowerment of people with disabilities vary throughout the region. Whereas in one country, empowerment of a person with disability can be realised better through the direct and active participation of the disabled people themselves, it can be diametrically opposed by another country whose political system is more restricted. Due to serious restrictions in the systems of Indonesian Government, the extent of community participation and mobilisation in provision of services for disabled people has to be carefully drawn out. Holding too many community meetings and mobilisation of community
resources is not encouraged by the Indonesian Government.

The Indonesian Government estimates that approximately 3.5% of population has some disability, which would total approximately 7 million people (total population 200 million). Poverty, ill health, malnutrition, coupled with ignorance remain common phenomena like any other developing nation. Most of the non-governmental organisations are charity and/or welfare oriented. The majority of them are working for or on behalf of disabled people. Only a few are organisations of people with disabilities. 

More than ever before, the priority ranking that an issue or a group receives in policy and funding decisions is directly proportional to intensity, quantity and quality of media coverage.[2] Even individual decisions to mentally switch off or tune in concerning disability matters is affected by this phenomenon. In the media-driven, flavour-of-the-month approach to development, ordinary persons with disabilities lose out. There is no glamour in disability issues. The everyday struggles of people with disabilities are not subjects for media sensationalism. To sensationalize disability issues in order to attract media attention is itself contradictory to the principles of equalization. Insensitive media portrayal mirrors and reinforces societal attitudes towards “cripples”. [3]

A basic issue is the need to reconceptualize public awareness activities in the disability field in terms of strategic campaigns based on clear understanding of target audience profiles, and well-defined objectives specifying the changes to be achieved. These must be complemented by positive living examples of the truth of the messages delivered. The efforts in progress will make it easier for societies of the next century to come to terms with a broader spectrum of shades of ability merging into shades of impairment and disability at different stages of life, rather than a stark black-white divide between the “normal” and the “disabled”.

Conclusion

Myths, stereotypes and negative attitudes to disability will continue to create barriers unless action is taken to ensure a more equitable access to services for disabled individual. Alleviation of poverty through provision of better health and education services will help ensure all individuals; disabled and non-disabled are able to function in their society to the maximum of their ability. It will also help in assuring disabled people are accepted members of society and not marginalised. Ensuring education and training of people with disabilities with their non-disabled peers will help in dispelling the myths and stereotypes held in many societies. It will help erase the ignorance about disability that leads to the continuation of myths and stereotypes. Legislation is needed to ensure that this happens.

References


This paper was presented at the 8th World Down Syndrome Congress in Singapore, 14-18 April 2004.
News on Numicon

Research project and guidebook

At the end of the summer the Numicon research project the Trust has been conducting will be coming to an end. At the moment Dr Joanna Nye is writing up the results of the first year of the project and an article on this will be appearing in the next issue of DSNU. In addition she is writing a practical guide to adapting the Numicon scheme for children with Down syndrome to be published in Autumn 2005. (The research project and the writing of the guidebook is funded by the Esme Fairbairn Trust.)

Training workshops

Forthcoming workshops in Portsmouth

Jo will be running a day workshop on using Numicon with children with Down syndrome at the Sarah Duffen Centre on 10 October, and will run a short workshop at the 4th International Conference on Developmental Issues in Down Syndrome (15-18 September 2005).

Training at other locations

Jo will also be available to run workshops across the UK and worldwide from the Autumn term, so if you are interested in hosting a workshop in your area please see the Trust Services catalogue for more details (e-mail enquiries@downsed.org for a copy). Training can be tailored to meet your needs so please contact the Trust if you would like to discuss this further.

Branch contacts

**Berkshire:** For more details of the Branch’s activities contact: Colin Stonehouse: c.stonehouse@ntlworld.com tel: 0771 904 3603 or 01344 823476.

**Bristol:** The Branch runs Early Development Groups every Monday at Henleaze & Westbury-on-Trym Community Church, Eastfield Road, Westbury-on-Trym, Bristol. For more details contact: Annabel Dixey, tel: 0117 9624735 or Marie-Louise Cook, tel: 0117 9686893

**Canterbury:** The Branch meets every 3rd Monday at Northgate Community Centre. 9.30-12.00. For more information please contact: Sarah Kent on 01227 453926 or e-mail AlexHector@aol.com

**Darlington:** A very enthusiastic group, led by Maggie King, a teacher and mum to baby Alexander, have established a Darlington Branch in North East England this year. For details of their activities please contact Maggie on king_maggie@hotmail.com

Primary school inclusion video

We are just about to start shooting video footage for a brand new video/DVD on the effective inclusion of children with Down syndrome at primary school.

The majority of children with Down syndrome can now expect to attend a local mainstream primary school rather than a ‘special’ school. The Trust is widely recognised as one of the leading authorities on the effective inclusion of children with Down syndrome in the mainstream classroom, based on two decades of extensive experience in promoting inclusion and providing practical support to schools including these children.

Our Down Syndrome Issues and Information books provide a comprehensive explanation of the principles and practices of effective inclusion.

However, we receive many requests from parents and teaching staff asking for introductory materials about effective inclusion at primary school. Video/DVD provides the ideal medium for conveying key information and providing real-life examples filmed in the classroom.

Our new primary school inclusion video/DVD will summarise key evidence from research, outline practical strategies and demonstrate examples of effective inclusion of children with Down syndrome at primary school.

Current progress

Filming for this video is taking place in local Portsmouth schools during June and July. We plan to launch this new video/DVD in autumn 2005.
early intervention and school education - from research to practice

A unique opportunity to participate in the leading international conference

Join the world's leading researchers and practitioners to explore the latest research into all aspects of development for children with Down syndrome

Provisional programme

Friday 16 September: The Early Years and Intervention - keynote speakers
Deborah Fidler (Colorado State University, USA)
Instrumental and social development in toddlers with Down syndrome: Implications for intervention
John Oates (Open University, UK)
How can social interactions best foster the development of infants with Down syndrome?
Robert Hodapp (Vanderbilt University, USA)
Neglected issues in early intervention for children with Down syndrome: Families, health, and problems during the earliest years
Gerald Mahoney (Case Western Reserve University, USA)
The role of parents in early motor intervention
Dale Ulrich (University of Michigan, USA)
Treadmill training and infants with Down syndrome: The impact on walking and cognitive behavior
Naznin Virji-Babul (Down Syndrome Research Foundation, Vancouver and University of Victoria, Canada)
Perceptual-motor deficits in children with Down syndrome: Implications for intervention

Saturday 17 September: Speech, language and literacy - keynote speakers
Robin Chapman (University of Wisconsin, USA)
Language learning in Down syndrome: The speech and language profile
Stephen Camarata (Vanderbilt University, USA)
Integrating speech-intelligibility and language intervention in Down syndrome
Katie Alcock (University of Lancaster, UK)
Oral movements, motor control and language
John Clibbens (University of Plymouth, UK)
Signing and communication development in Down syndrome
Charles Hulme (University of York, UK)
Reading development in children with Down syndrome: Relationships with oral language and phonological skills
Sue Buckley (Down Syndrome Educational Trust, UK)
Teaching reading to teach talking

Sunday 18 September: Education and barriers to learning - keynote speakers
Stefano Vicari (Children's Hospital "Bambino Gesù", Italy)
Memory and learning
Monica Cuskelly (University of Queensland, Australia)
Delay of gratification in children with Down syndrome: Parental strategies for encouraging waiting
Speaker to be confirmed
Challenging behaviours – how do we understand and manage them?
Margaret Woodhouse (Cardiff University, UK)
Maximising vision: Dealing with visual problems in children with Down syndrome
Patrick Sheehan (Royal Manchester Children's Hospital, UK)
Otological and hearing management – The evidence and what's new
Bob Black (Down's Syndrome Association, UK)
Access to education: A report on barriers to education for children with Down syndrome

a full programme of parallel afternoon sessions is available at http://www.downsed.org/conference2005
Forthcoming training events

Training at The Sarah Duffen Centre, Portsmouth, 2005

Monday 13 June 2005
Workshop: The Numicon approach to teaching number - an introduction

Monday 20 June 2005
Workshop: Meeting the educational needs of children with Down syndrome in mainstream schools - Secondary

Monday 19 September 2005
Workshop: The development and education of children with Down syndrome in infancy and preschool years - overview birth-5

Monday 3 October 2005
Workshop: Meeting the educational needs of children with Down syndrome in mainstream schools - Primary

Monday 10 October 2005
Workshop: The Numicon approach to teaching number - an introduction

Monday 7 November 2005
Workshop: Speech and language development for children with Down syndrome from birth to teenage years

Monday 14 November 2005
Workshop: Supporting the development and education of children with Down syndrome

For further details and booking forms, send for our Services brochure,
tel:+44 (0)23 9285 5330, or e-mail: brochures@downsed.org

24 June 2005: Including children with Down’s syndrome, East of England Showground Peterborough. A full day of workshops for teachers and support staff working with pupils with Down’s syndrome. A DSA UK Education Consortium event in collaboration with the Peterborough Area Down’s Syndrome Group. E-mail: lalabaf@downs-syndrome.org.uk for further details

9 July 2005: Early Years, Langdon Down Centre, Teddington. This conference will be of interest to parents and carers of children with Down’s syndrome aged between birth and 5 years and also the professionals who support these families. There will be workshops on Speech and Language Development; Welfare Benefits and the SEN Statementing Procedure. Cost £20 to parents/carers and £80 for professionals. Contact Gill Hayes for more details on 01474 747 401 or e-mail gildsasoutheast@hotmail.com.

http://www.downs-syndrome.org.uk
Aims and scope

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

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

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

Guidelines for contributors

**Longer articles and reviews**

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

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

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

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

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

**News**

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

**Correspondence**

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

**Editorial review**

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

**Submissions**

Papers submitted to the Journal should be sent to:

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

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

Manuscript layout

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

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

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

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

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

References format

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

Articles

Chapters

Article (World Wide Web reference):