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We are seeking additional members for the Editorial Board. If you are interested in assisting by reviewing submissions and/or contributing reviews or articles, please contact the Editor at the address shown below for further information.
We would particularly welcome advisors from a variety of countries.

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This issue has several themes, inclusion in education at secondary school, healthy lifestyles and weight management and personal development and sexuality. It also has a focus on the adolescent years in those topics.

The first article provides practical advice on inclusion at secondary school level (11 to 16 years), based on experience in the UK. The first author, Gillian Bird, has been supporting children with Down syndrome in mainstream schools as part of her work for The Down Syndrome Educational Trust, since 1988. During that time inclusion has become widely accepted and in some areas some 70% of children with Down syndrome start their education in mainstream primary schools. However, only 25% complete their education in the mainstream secondary schools in the most inclusive education areas according to a 1997 survey. In most areas until recently, children were moving to special education between 9 and 11 years. With more political and legislative support for inclusion in the UK as elsewhere, this is changing and more children with Down syndrome are completing their education in the mainstream. This is reflected in the demand for training from secondary schools and we have been able to learn from the experience shared on training days as well as our direct work in schools.

The article emphasises the importance of whole school training in disability awareness and the aims and philosophy of inclusion as well as information on expectations and development for people with Down syndrome. Training is a key to success and should also ensure that staff are able to differentiate the curriculum and support learning successfully. They should also be confident in supporting the social and personal development needs of individual students. The skills and knowledge that lead to successful inclusion for the teenager with Down syndrome are the same as those that lead to successful inclusion of the majority of pupils with special needs. The article covers social needs, friendships and life skills as well as accessing the curriculum. It also provides guidance on the range of academic levels that may be expected and on the particular needs of teenagers with Down syndrome.

A survey of adolescent development recently completed by The Down Syndrome Educational Trust and the University of Portsmouth provides clear evidence of the benefits of mainstream education for the communication skills, academic attainments and social progress of the young people. The main findings are outlined in the article and a more detailed account of the survey, which covers issues for families as well as schools, will be in the next issue of Down Syndrome News and Update (2.1).

Still on the theme of inclusion, we review a Dutch video on successful inclusion in primary school, Down to Earth, which is available with English subtitles, in the Review section. This video will be a valuable addition to training resources on inclusion for many countries. Viewers in the UK may be interested to note that the children do not have support assistants and consider the effect that this has had on the class teacher's role and responsibility.

The second article in this issue by Stephanie Lorenz, reports the main findings of a survey of families' experience of inclusion in the UK. Stephanie collected information from over 400 families by questionnaire. Stephanie is well known for her publications, training and consultancy work in support of inclusion. Her study also highlights the variation in provision around the UK with the most inclusive authorities having 80% of
primary and 50% of secondary age children with Down syndrome included and some having only a minority of primary and no secondary pupils included. Stephanie discusses implications of her findings for good practice in schools in relation to models of support, working as a team, support for support staff and accessing the curriculum. She concludes that the key factors for successful inclusion are a positive attitude to inclusion of the child throughout the school, a flexible approach to the use of support staff, ownership by the class teacher of the child's learning programme, good communication between school and parents and support for the school from the Local Education Authority.

The health topic in this issue is weight management and we have three articles by Joan Medlen, a dietician from Portland, Oregon in the USA who is also the parent of a son with Down syndrome. Joan has provided the advice for three age groups, early childhood, school age and adolescence and adulthood. The articles are clear and practical. They provide guidance on nutrition and healthy eating and also on practical strategies for daily routines that will help the reader to implement the advice. The articles are reprinted with permission from the publication Disability Solutions, which Joan founded and edits.

Weight management can be a significant difficulty for many children and adults with Down syndrome, leading to health problems and seriously reducing their activities and quality of life. Most parents know this but it is not easy to control children's weight. However, if healthy eating and exercise habits can be established in childhood it will help the young person later in life. Readers will find the advice in Joan's articles is clear and attainable within most families' lifestyles.

Continuing the adolescent focus of this issue, our next contribution from Lel D'aegher in Sydney, Australia is on personal development and sex education for young women with Down syndrome. Sex education and sexuality are still a concern for most families with a child with Down syndrome. In this article, Lel describes a project developed by the Down Syndrome Association of New South Wales to work with a group of mothers and their daughters with Down syndrome on these issues. The mother and daughters met over a period of a year and discussed development and sexuality. The project resulted in the publication of resource materials that can be used with parents and young people entitled Talk to Me. This is an innovative project and the model, where parents and professionals work in a really collaborative way to pool their expertise, is one which should be extended to many other issues. Too often we have either the parent view or the professional view, both valuable but only one side of the picture.

In the computer section Neil Sleight, a computer consultant in the UK, provides a guide to the purchase of a home computer, for those who are not yet familiar with computers. There is general agreement that most children with Down syndrome can learn very effectively by using the computer. The computer makes use of their learning strengths and helps to get around their learning weaknesses. Learning from listening is really difficult for children with Down syndrome compared to learning from looking at visually presented information. Auditory speech processing and auditory memory are weak, visual processing and visual memory are strengths. Responding to a question or task by speaking a sentence is difficult, responding by pointing to the right answer is easier. The computer is therefore a very positive tool.

In addition, children will often work for longer periods on the computer than in other desk or classroom situations. The learning can be under their own control and go at their own pace. For parents and for teachers there is yet another advantage. Good software provides teaching programmes that are planned for you. The software has improved dramatically in the last few years and in the review section we include a review of Inclusive Writer from Bob Black. This is not a starter programme but is a very versatile support for literacy development as Bob indicates.
Last but by no means least, in our Letters section we have a letter from Sarah Duffen. She is working to help us establish a letters section so do please help by writing to us. We welcome letters from young people with Down syndrome, parents and professionals. Sarah describes her outward bound activities in Devon with the Women’s Challenge club. Sarah is very competent in many sporting activities, including caving, canoeing, swimming, water skiing and skiing.

This is the last issue of our first volume of *Down Syndrome News and Update*. We are developing an international range of contributors and we hope that you have found the issues informative and interesting. Pressure of work for the small staff team at The Down Syndrome Educational Trust has led to slow production of the issues for which we apologise. The next volume will include articles on adolescence, autism, social skills and behaviour, numeracy development, accessibility issues in information technology, new Internet resources, and more.

We would like feedback from our readers on this new publication, so do write and tell us your views.

References

The Congress is the first World Congress on Down syndrome to be held in the Asia Pacific region. It is a tremendous opportunity for people with Down syndrome, their families, and professionals to hear world renowned speakers address the latest developments in many areas affecting people with Down syndrome. An exciting social programme, highlighting the talents of people with Down syndrome, will be a feature of the Congress.

The theme for the Congress is: *Down Through the Ages Towards the New Millennium: Attitudes Change*.

The format of the Congress will include invited speakers, addressing the cutting edge social, scientific and medical issues relating to Down syndrome. Workshops will allow parents and professionals to address specific issues relevant to people with Down syndrome of all ages, and there will be poster sessions and a trade display. A concurrent programme for people with Down syndrome will be an integral part of the Congress, and the Australian Future Adult Advisors Group, (a group organised by and for people with Down Syndrome over 15), are assisting in the formulation of this programme.

Various research groups from around the world will be giving symposia and/or workshop sessions on their work. Speakers include Sue Buckley, University of Portsmouth and The Down Syndrome Educational Trust, UK; Roy Brown, Flinders University; Anne Jobling and Monica Cuskelley, The University of Queensland; Carl Pasons, La Trobe University and Digby Elliot, McMaster University, Canada.

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MEETING THE EDUCATIONAL NEEDS OF PUPILS WITH DOWN SYNDROME IN MAINSTREAM SECONDARY SCHOOLS

Gillian Bird and Sue Buckley
The Down Syndrome Educational Trust

Summary – This article provides information and advice to secondary schools that are including a pupil with Down syndrome. The advice is based on our experience of observing and supporting individuals in secondary schools that are including pupils with Down syndrome in Portsmouth and South East Hampshire. It informs secondary schools that have not yet included a pupil with significant learning or language difficulties that the key to success is through developing systems and procedures for meeting the wide range of individual educational needs of all young people. The article emphasises the importance of developing opportunities for: (1) personal and social development, (2) teaching, differentiation and support for learning, and (3) training for staff on all issues related to disability awareness, inclusion and expectations for people with learning and language disabilities, including Down syndrome.

Keywords – Down syndrome, secondary education, inclusion

The benefits of inclusion

Inclusive schools are good schools for everyone

In the authors’ experience, where schools are sensitively and thoughtfully meeting the needs of many young people with special educational needs they are usually good at meeting most of the needs of young people with Down syndrome. These schools are often also achieving outstanding academic outcomes in General Certificate of Secondary Education and ‘A’ level examinations. For example, one of our local secondary schools has three teenagers with Down syndrome, each with a different profile of needs, successfully included and this school was near the top of the local league for examination results. There is no evidence that a school that is meeting the needs of pupils with special needs is going to adversely effect the education of the other pupils, the evidence is quite the other way around.[1]

Inclusive schools are better than special schools for pupils with Down syndrome

The evidence is that the teenagers with Down syndrome who are being educated in mainstream schools are gaining considerable benefits in academic skills, communication skills and social independence. We have just completed a survey of the progress of 46 teenagers in Hampshire, of whom 18 are in mainstream secondary education and 28 are in special schools. This study is an extension of the one we carried out in the mid-eighties [2] so
we are not only able to compare the effects of mainstream versus special education but also to see if today’s teenagers are benefiting from progress in the quality of education and in social attitudes. We have collected information on a wide range of issues including, health, behaviour, sexuality and social lives in addition to personal and social independence, communication skills and academic progress. We also have family views on their experiences and needs. A more detailed report of this study and its practical implications for families and schools will be the leading article in the next issue of Down Syndrome: News and Update (2.1) and a full research paper is in preparation.

The main point of relevance for this article and the education debate is that it is clear from our data that children with Down syndrome benefit from being educated in mainstream schools. The teenagers we describe as mainstreamed have received all their education in mainstream schools, as full members of the ordinary classes, not in special classes. This group are significantly ahead of their peers in the special schools on standardised measures of communication (receptive and expressive spoken language), literacy, and social competence. They are not significantly ahead on daily living skills (practical personal care). They display significantly less difficult and anti-social behaviour than those in special schools. There is no evidence that these two groups of children varied in ability when they went into the school system at five years of age. At that time, most of Hampshire was still sending children with Down syndrome to special schools but in part of the county mainstreaming was being supported. There is a wide range of ability in both groups of young people at the present time. There are young people successfully included in mainstream secondary schools who are less able in academic terms than many of those still in special education.

Little progress in special schools in 12 years

The progress of the teenagers in the special schools is not significantly better on any of the measures that we took in both 1987 and 1999, except on literacy and numeracy. We would argue that this reflects progress in the development of a more academic curriculum in most special schools. Progress in reading and numeracy are dependent on good instruction from the teachers. Progress in communication, social skills and behaviour may be much more dependent on the peer group and without the role models and friendships provided by typically developing children, teachers in special segregated schools cannot raise outcomes, however hard they try. The findings of our study support and extend to secondary level the conclusions of other research studies available to date, reviewed in a recent paper by Cunningham, Glenn, Lorenz, Cuckle and Shepperdson. They state “In terms of measures of academic attainment and self-sufficiency, there is little evidence to show that attending special schools is more beneficial than mainstream schools in the preschool and primary years; what evidence there is, indicates more advanced progress in mainstream settings.”

UK experience of mainstreaming

Most experience is in the primary age-range

Examples of good practice, publications and training to assist mainstream primary schools to meet the educational needs of children with Down syndrome are available nationally. In most education departments children with learning disabilities attend mainstream schools, with success usually linked with the school and supporting education department’s level of inclusion awareness, skills and development. The experience of the thousands of UK primary schools that have educated children with Down syndrome over the last ten years has helped to develop the expertise of teachers and other education professionals. Fewer young people have progressed through secondary schools, although in the past five years this situation has begun to change and significant numbers of pupils are currently in mainstream secondary schools. Many more young people and their parents are anticipating transfer to secondary schools in the future and the number of mainstream secondary school pupils with Down syndrome is expected to rise sharply.
Need for secondary training and information

Information based on the experience of secondary school staff, the young people themselves and their families is in demand by secondary schools and parents alike. It seems likely that the circulation of information and training will be led by organisations and individuals working to create opportunities and equality for people with Down syndrome, as it was in the past for primary mainstreaming [6/9/10/14] rather than through a centrally led national system of training, education and school development.

Need for a national strategy

It is right that schools should have the independence to meet each individual’s educational needs, free from labeling and associated expectations. However, the lack of clear national guidance may continue to contribute to the inequality of educational opportunity for children with Down syndrome. At present successful mainstream placement and quality of education are dependent upon the practice of the education department where the child lives and on the skills and attitude of staff working in the school attended by each child. Without adequate guidance and training the risk for widening the gap between best and worst practice for educating pupils with learning and language disabilities in secondary schools remains. We would like to see the same planning and support for inclusion on a national level as there has been for the National Literacy Strategy – that is the development of materials and a training programme that reaches all schools and includes staff at all levels including head teachers and school governors.

The educational needs of teenagers with Down syndrome

Access up-to-date information

Through research studies and by assessing children and teenagers with Down syndrome we are now better able to describe the development and academic progress of many children and young people with Down syndrome [15-27]. It is important that providers of training and schools use up to date research to inform staff, and that training information is regularly updated, as young people with Down syndrome are constantly benefiting from improved social, leisure and academic experiences as well as better health, family and community support services.

Recognise adult life expectations

All staff will need some training and understanding about each pupil’s individual profile of language and learning skills and how to support him or her to develop his or her skills in the social context of a large school. Staff are also likely to benefit from developing their understanding about the future expectations of pupils with Down syndrome for their adult lives. Most will be able to leave home, live in some form of supported housing, enjoy supported employment and lead quite ordinary lives in the community. Many will enjoy ordinary adult relationships with partners and some will marry. It is so important for teachers and families to recognise that the social, emotional and educational needs of teenagers and young adults with Down syndrome are mostly the same of those of other children and young people. Success in the community and in the workplace as an adult requires the opportunity to continue to grow and to learn in the mainstream with those who will later become neighbours and work mates. All young people with Down syndrome will do better in life with the continued support of a good mainstream secondary school as well as continued support from their family and friends.

A wide range of individual needs

Like all young people, individuals with Down syndrome are different from each other and each will need his or her individual educational needs met in school. Young people with Down syndrome may have only mild learning difficulties and be little different from other slow learners in school, others have more significant difficulties. Some will come into secondary school with Reading Ages of 8 years to 9 years, others may have only limited independent reading skills. The same variation will be seen in number abilities and in gen-
eral and subject specific knowledge. In terms of behaviour and personality, young people with Down syndrome vary just as widely. Most are sociable, well-behaved and sensitive individuals, others enjoy being more challenging in the mischievous sense. If an individual engages in really difficult behaviour then we need to look for the causes because it means some aspect of his or her school life is not being planned to meet his or her needs appropriately. Some are shy and some are outgoing, some anxious and some confident.

Dispelling myths

The mythology of placid, stubborn and music loving individuals is as described – myth. So is the notion of ceilings or plateaus. All the young people that we work with or have studied continue to grow, learn and develop all through adolescence and early adult life. Indeed, adult life and independence often seems to offer a spurt to individual growth. While it is important to emphasise individual differences, there are some difficulties that are associated with Down syndrome and influence the educational progress of all young people to some degree, in particular language and working memory difficulties.

Language and learning disabilities are associated with having Down syndrome

Delay in speech and language skills and in working memory development is to be expected for all teenagers with Down syndrome. Most young people with Down syndrome will not have clear and fluent expressive speech. [28-31] They will have difficulties with phonology and articulation, so words are not always easy to understand. In addition, they have difficulty forming long sentences with all the grammar correct. This results in rather ‘telegraphic’ speech which may be difficult for teachers and friend to always understand. The majority of young people have much better comprehension of language than their spoken language suggests, so their understanding is at risk of being underestimated. Most young people will also have short term or working memory difficulties.[32-37] These differences make it more difficult for people with Down syndrome to access, understand and process information at the same speed as people who do not have cognitive and language delay, but they do not prevent them from learning many of the same things. They need the information presented in a clearer, more ordered way, with explanation about the links and associations between information to build their knowledge system. They may need more time to learn and understand and more practice to be able to apply their knowledge. Like everyone else, they learn more and at a faster rate if interested or motivated.

At the time of transfer to secondary school many children with Down syndrome can understand what is said and asked of them in school, provided the vocabulary used is within their knowledge and the topics are within their life’s learning experience from home and their previous school.

Description of speech and language skills from formal assessments can be misleading to staff unfamiliar with the tests. For example, an age equivalent for understanding grammar of around 5 to 6 years is good for an 11 year old who has Down syndrome. This level of understanding is sufficient for understanding the grammar of everyday language at school and at home, including lesson delivery, given that the pupil will have an assistant to repeat what is required of him or her, write down key points in a list, and help to ensure that he or she understands and can remember. Vocabulary knowledge is typically higher than levels for grammar, and is sometimes age appropriate.

Speech and conversation skills vary enormously and some young people experience great difficulties in learning to speak clearly and in grammatically correct sentences. This does not mean they understand less than more articulate pupils with Down syndrome. Many pupils will also have sufficient use and clarity of spoken language to convey their meaning, although rarely does expression of ideas in language match their understanding. Communication can be easily affected by situational factors. A hostile environment, unsympathetic listener, anxiety, perceived pressure, embarrassment or lack of confidence may result in discrepancies in the individual person’s communicative skills and performance in and out of class.
Delays in gross and fine motor skills are associated with Down syndrome

These will influence handwriting ability and participation in sports in particular. Information about the pupils development of motor skills, agility, participation in sports, issues related to health (e.g. heart) and fatigue levels is also relevant for training staff, especially on a large, multi-level site or where location of the Learning Support Department is at a distance from many of the classrooms.[38]

Academic attainment levels, UK curriculum

In our experience, pupils around the age of transfer to secondary school often have attainments levels between W (working towards level 1) and level 2 (average for children aged 7 years) on the UK National Curriculum. Their skills continue to develop, with some pupils working at around level 3 (average for children aged 9) towards the latter part of their secondary education. At transfer age 11 to 12 many pupils have begun to understand money, are learning early multiplication and division and to tell the time. Literacy attainments are usually to a higher standard than achievements in numeracy, and pupils are often working at around a 6 to 7 year level at the age of transfer. Some pupils have literacy skills beyond this level at age 11, and may be above their chronologcal age in reading ability, but may still have weaknesses remembering and understanding the information they are able to read, depending upon their language knowledge. Some pupils with lower levels of skill attainments have similar levels of understanding and good social skills that help them to succeed in secondary school. Social and academic skills will continue to develop with increasing age, school and life experience.

We have observed that secondary education has some advantages compared with the last two years prior to transfer from primary school. Often Learning Support is better developed and resourced in a large secondary school and pupils benefit from working with a variety of specialist subject teachers.

The curriculum and differentiation

Not outside the range

In our experience, there are usually other pupils in large comprehensive secondary schools working at similar levels of academic achievement to pupils with Down syndrome, particularly in literacy and numeracy. If there is a need for secondary school staff to become more skilled at meeting the varied needs for a wide range of pupils, schools can arrange training for subject teachers on differentiation and lesson planning.

Each individual needs a different amount of support or help to access the information and participate in lessons, and with adequate differentiation by the teacher, clear visual resources or visual aids, and help as necessary for each individual, all lessons can be successful learning experiences for the majority of young people with Down syndrome.

Teacher’s responsibilities

It is the teacher’s responsibility to ensure that the standard of differentiation required is achieved and to identify areas for development when working with Learning Support Assistants.

Arrangements between the teacher and Learning Support Assistant for the level and type of support the pupil needs during whole class teaching, working in pairs, small groups, independently and for peer tutoring will also need to be established and developed. Communication between subject teacher’s, specialist support teachers and Learning Support Assistants supporting different subjects is essential and school should plan for meeting time or establish other means of communication and feedback between all involved. Arrangements for managing pupils individual education plans (IEP) and developing cross curricular skills offer opportunities for improving communication channels.

Well-structured lessons

Lessons should be well structured with an outline of content and aims at the beginning, summary of key points as the lesson progresses and a review at the end. If transitions are signalled clearly, and the
Lesson is delivered with enthusiasm, clarity and a rapid pace then principles for good teaching have been applied. If a teacher communicates a brief and simple form of each lesson to the pupil and assistant, ideally with written notes, and obtains resources or indicates to the Learning Support Assistant how and where to obtain resources and activities to teach and illustrate key points, then most lessons can be accessible to the pupil.

Lesson plans in advance

We think it is good practice for lesson plans to be given to assistants in advance of lessons, to enable the assistants to be more confident and have more authority within the lesson. This is especially important for assistants supporting pupils with variable behaviour. Assistants may also have their own ideas for suitable resources, pictures and practical materials, and knowledge about the lesson in advance enables them to use their skills as Learning Support Assistants to the full.

Main points and small steps

Trained and experienced Learning Support Assistants will know how to break down information into small steps, will try not to teach too many concepts at once and can help to present work and activities visually. Writing frames are particularly helpful for differentiating input (in all subject areas) as well as aiding written output. Pupils should be encouraged to convey their understanding and ideas through writing, with key words, lists or maps, so that they develop the main purposes of writing, without the simultaneous need to construct grammatically correct sentences.

Additions to serial presentation of information through flow diagrams, summaries or continuous text, include concept maps, story webs and boards and other visual ways of representing information and identifying associations. These strategies are useful for input and output of information and are particularly useful for those with writing difficulties or who find it difficult to plan and sequence a series of ideas and sentences. Creating grammatically correct sentences can be targeted separately, or after the main points have been established. Work on sentence formation will help to develop the pupil’s spoken language skills. These methods can be used to assess comprehension and can be applied to social as well as academic learning.

School development for inclusion

Secondary schools are working towards becoming more inclusive for all children. The number of pupils with significant needs influences the priority a school gives to creating change and developing adequate school procedures to achieve success. This point is made in an article about a secondary school that accepted a relatively large number of pupils with moderate and severe learning difficulties in one intake due to policy change in the London Borough of Newham [39].

Staff need training and support

At the classroom level, not all staff are willing or able (without help and support themselves) to understand, teach, plan lessons, prepare work and provide homework for their new pupil with significant learning difficulties. It is our experience that most are willing to try and are usually surprised by their pupils’ abilities as well as their own skills. We may have experience locally of schools with particularly good attitude, intentions and procedures for delivering and developing inclusive practices, and hope that we do not have an over positive view of the current state for secondary age pupils with Down syndrome.

Learning Support is a central facility of the school

If schools are planning to develop excellence, the Learning Support Department, a room for preparation and display of resources, a photocopier, computer(s) and colour printer should be located in the ‘heart’ of the school, central for easy access by teaching staff, support staff and pupils. ‘Learning Support’ will be an important and integral part of any comprehensive or non-selective school. All staff should know about the procedures for using facilities and obtaining resources for all pupils with learning disabilities and other individual needs that they teach. The design of the Learning Support Department should allow room for preparation and storage of resources and room or other areas for small group work. The Special
Educational Needs Co-ordinator (SENCO), support teachers and learning support assistants should have adequate office accommodation and other spaces for working and training. Staff (including Learning Support Assistants) should have flexible access to rooms, photocopiers, computer facilities, library, teaching resources, and publications for staff development and training.

Understanding funding

Knowledge about the school budget and training in allocation of funds towards learning support and for materials for pupils with special educational needs is also advisable. Many teachers do not understand the funding for meeting pupils needs, and honesty about funding arrangements and the school’s responsibility to spend its money for pupils with additional needs for the benefit of those pupils is likely to be helpful. Pupils with additional needs do cost more money to educate and include and funding arrangements allow for this. Spending extra money on pupils with additional needs does not ‘take away’ resources from others. Initial outlay on books and resources or staff training, initiated due to the arrival of a pupil with Down syndrome, will benefit many pupils who do not have Down syndrome and help the process of making the school more inclusive for all pupils.

The responsibilities of Heads and Governors

School Governors should be included in training, and senior management must take responsibility for developing good practice in this field. At training days we occasionally meet special educational needs co-ordinators and heads of department that are very concerned about how to gain co-operation of staff to differentiate work to the standard required, as well as for treating all pupils with equality, respect and sensitivity. It is clear that these issues are not about having a pupil with Down syndrome, they are about weak practice for many pupils and require action from the senior management of the school. Fortunately, such schools are in a minority in our experience, although all schools require more work on differentiation to the level that enables greater numbers of pupils with moderate and severe learning difficulties to be successfully included.

New challenges for pupils

Size of school and independence on site

Most of the young people we know have adapted extremely well to secondary schools they have transferred to with other members of their primary school. Learning how to function in a large school (up to 1900), move location from lesson to lesson and be a member of a tutor group has not been difficult. Many pupils benefit from a clear plan of the school, colour coded, showing subject areas and key staff names. Concerns about the pupil’s ability to adjust to an increased school size has often been raised as reason for not continuing from a primary to a mainstream secondary school: our experience would suggest the opposite – that the experience of responsibility and independence in a large community school has been positive for most young people. Secondary school sites, although large and complex compared with most primary schools, are small compared to the wider community we hope the pupils will live in as adults and they provide excellent learning opportunities for independently moving around in a monitored environment. Many pupils experience more freedom and responsibility than they have ever been allowed in their life before and enjoy this.

Change of location for lessons

Change of location, pupil groupings, subject teachers and sometimes a change of Learning Support Assistant can be refreshing from the pupil’s point of view. The short breaks between leaving a lesson and joining a new lesson allow for valuable social interaction as well as exercise. When staff think pupils are ready or when pupils request to do so, they should change from lesson area to lesson area independently, meeting their assistants at the arranged classrooms, conduct themselves in tutor times and spend lunch and break times independent of additional adult support. Typically, this happens gradually during the first year. If pupils need support at these times it is preferable to use the support of peers rather than adult staff support.
As for all pupils, it is easier to transfer and share a tutor group with at least some known peers from primary school. The support of friends will continue to be needed as pupils progress through school. It is socially inappropriate for pupils to repeat year groupings within school.

**Using timetables**

Mastering the use of a timetable has been straightforward for most pupils. Visual symbols for each lesson can be added to make the timetables more interesting using information technology. The use of a homework timetable needs to be learned and help is needed at home and from school to learn this new skill. Timetables for lessons and homework can be made easier to follow by clear presentation and use of colour.

**Homework**

Homework should be planned to reinforce teaching of the ‘main parts’ the pupil needs to learn. Set homework equitably for ability: homework is important but must be able to be completed by the pupil.

**Type and use of support**

Schools, parents and the Local Education Authority should explore issues relating to support on an individual pupil basis. This will ensure that each individual’s learning and language needs continue to be supported when he or she transfers to and progresses through secondary school. It must be stressed again that pupils with Down syndrome are not all the same. Support for many pupils with Down syndrome is in the form of a learning support assistant, who, under the guidance of the teacher, sets work that can be completed independently, either in one chunk or in smaller pieces, returning as necessary for explanation, discussion, or summary near the end of the lesson. Learning Support Assistants should not sit next to pupils all of the time.

Pupils in the secondary schools we are most familiar with receive around 25 hours of learning support assistance and some pupils receive teaching support in addition to this. The latter is more likely to be necessary if the school does not have special teaching arrangements or focused teaching groups for children of lower ability.

Where ‘setting’ is in place, consideration should be given to placing a student with Down syndrome in a set with well motivated peers to ensure that the student has access to good models of learning and behaviour. Most pupils can manage with more than one or two assistants supporting them, but too many assistants can lead to inconsistency in behaviour management (which is important for some pupils) and lack of continuity between lessons.

**Meeting additional needs**

**Focused teaching groups**

Meeting individual needs by attending a focused teaching group for literacy [40], numeracy, conversation, social skills, life skills or studying an alternative to General Certificate of Secondary Education course is unlikely to present difficulties for the pupil in a school where going to different locations for different subjects or purposes is normal. Difficulties may arise if choices are made without the involvement of the pupil and discussion with the pupil’s parents. Subjects that are hard for the pupil at the curriculum level may still be favoured by a motivated and supported pupil, and we advise that school staff do not prejudge what subjects each individual will enjoy and learn from based on their assessed abilities.

**Speech and Language Therapy**

Most pupils will benefit from continued speech and language therapy through their teenage years. Even pupils with clear, grammatical speech will benefit from help to continue to improve their understanding, knowledge, conversation skills, appreciation of themes and topic changes and social use of language. Many pupils may also have issues relating to speech clarity and require continued work to improve their production and use of spoken language. Guidance for staff on how to facilitate practice and help develop confidence in talking for different purposes and in different situations will also be helpful.
Behaviour

Pupils with additional needs in the area of behaviour rarely fall outside of the range of needs of some other pupils in school. If a pupil has behaviours that are considered very difficult to manage in school then a secondary school with strengths in including pupils with emotional and behavioural difficulties is more likely to be successful for meeting this pupil’s needs. Most secondary schools have some pupils with emotional and behaviour difficulties: ways of establishing and communicating individual arrangements, working within the whole school behaviour plan and the co-ordination of curricular and pastoral systems will apply to all pupils with these additional needs. The secondary school’s Educational Psychologist should be able to help with individual arrangements if the team in school needs more help. Knowledge based on research into the range and types of behaviour difficulties experienced by adolescents with Down syndrome can be informative,[41] especially if paired with evidence of successful interventions. In our experience, the most successful plans at school have been based on the principles and knowledge about behavioural interventions for all young people of secondary age. This includes understanding of special needs as a function of social context and using information gained from assessment, partnership with parents, quality of relationships, achievement in the curriculum and issues related to differentiation.[42/43]

Qualifications: developing alternative accredited courses for key stage 4

Change in this area has been rapid in the last two years and will continue to be so. New courses are being accredited, developed and introduced in most secondary schools as alternatives and additions to General Certificate of Secondary Education. The most recent development in alternative accreditation at key stage 4 is the introduction of the new Entry Level which is designed to recognise and accredit achievement for pupils at key stage 4 who are working below grade G in General Certificate of Secondary Education or foundation level of General National Vocational Qualification. If a team of staff have not yet been assigned responsibility for finding out about alternatives and their suitability for their pupils and staff, then the arrival of a pupil with Down syndrome will make this an additional need for school. New courses may not be needed for several years, but the school should have development in this area and be ready for the needs of the pupil with Down syndrome in years 10 and 11. Most pupils with Down syndrome take some General Certificate of Secondary Education courses, and are likely to continue to do so even with an increased range of alternatives. In addition, most awarding bodies have developed Certificates of Achievement which are designed for pupils at key stage 4 who are at levels 1, 2 or 3 or who are borderline General Certificate of Secondary Education candidates. Many of these are co-teachable with the General Certificate of Secondary Education courses.[44]

Creating opportunities for social learning

Pupils with Down syndrome vary widely in their social development and their skills will continue to develop with increasing age and experience. To help young people learn they need suitable learning opportunities: schools, families and communities need to work together to enable learning and development to take place.

A social curriculum should be an integral part of education in school

Social skills do not develop without help for many pupils who do not have learning disabilities, but having a learning disability places children and young people at greater risk of missing opportunities for learning essential life skills at certain stages of their lives. All involved need sensitivity to these issues and to work together to best help these young people. Pupils with Down syndrome may not learn some social skills as quickly as some other pupils in secondary school, but there are many years in which to develop and learn through continued education and social learning opportunities.

The pupil with Down syndrome should fit within a framework for the social development for all
pupils. If they do not, then this framework may benefit from being made wider. If pupils are far behind peers in terms of social skills, school and parents should work together to target and improve social skills and behaviour. Encourage staff to look beyond the person’s learning disability – an academic or cognitive assessment is but one dimension on which to measure and judge a person. High intelligence does not guarantee good social skills, good mental health or a successful career and staff should look for, reward and nurture positive characteristics for success as members of society in all pupils. All staff must treat the pupil with Down syndrome with the same respect as others of their age.

Relationships and social context matter

Typically, pupils with Down syndrome will know if they are not liked and can react badly if not treated well or treated equally. They may be less able to deal with their perceptions, to discuss them with others or to develop the ‘buffers’ that help many other pupils cope with difficult situations at home or school, through close friendships with peers. They are likely to be less able to protect themselves or compensate for poor treatment by teachers or other pupils.

Across the curriculum

Staff should try to ensure that skills are taught in ways that promote social inclusion, with respect for each individual’s social learning needs and school context, across all curricular areas. Temporarily, this may not always be possible for some pupils in some teaching situations, but should always be a goal to be working towards.

Equality and responsibility

There may be more areas of equality than staff initially think in that some of the secondary curriculum is new to all pupils, for example, modern languages, learning more about music, new sports, new art and craft or dramatic experiences. The person with Down syndrome may not be particularly disadvantaged and may be as confident as others to try new activities, depending upon personality and learning style. Offering responsibilities in lessons, at break times, and in extracurricular activities, and rewarding appropriate, thoughtful and responsible behaviour during lessons will help to develop self confidence and self esteem.

Extra curricular activities

Most secondary schools have a range of extracurricular activities. If these seem too specialised or aimed at developing high levels of achievements in specific fields, then perhaps extending the range of clubs that can include pupils of varying ability should be a priority for school.

Access to the learning support department at lunch time, for access to games and activities, for conversation, or for learning and social support should be considered, as well as participation in a homework club. Pupils should visit and watch a range of school activities so that they can make their own choice of extracurricular activities. Encouraging a pupil to join several school activities and having social activities on the pupil’s IEP will help to offer a range of opportunities for social learning outside of the classroom.

Personal and Social Education

Personal and Social Education (PSE) should not be focused exclusively on the needs of the pupil with Down syndrome. It should also include the needs of the staff and other pupils, and enable them to develop their understanding of the needs and expectations of pupils with learning disabilities. ‘Citizenship’ training is in place in many secondary schools, even if only in a small way. With more awareness, staff and peers are more likely to give appropriate feedback when interacting with the pupil around school, which will have positive effects on all aspects of social learning, including behaviour.

Friendships

It is likely that the nature of the ‘mutuality’ of some friendships at mainstream school during adolescence will change, although the support of friends who do not have Down syndrome can continue through to adulthood, especially if the person with Down syndrome has attended his or her local community school and continues to live in his or her community as an adult.
Informal friendships

Friendships can be helped to flourish informally, through peer support in class and around school. Even a little staff awareness of the pupils friendships and how to enable these to continue to be maintained, or at least not be extinguished through thoughtlessness, can make a significant difference to an individual’s life. An excellent book by Debbie Staub entitled *Delicate Threads* [45] provides information on the importance of friendships and the benefits of inclusion, and provides useful suggestions for families, teachers and others interested in supporting children and young people’s relationships in inclusive schools and in the community. Although most of the examples are friendships in younger children, the issues and advice discussed can be extrapolated to teenagers.

Planning peer support

Relationships can also be helped to develop through planning and structuring peer support for specific activities, functions, events and times of the day, in and out of school. Many schools use different ‘buddy’ systems and train their ‘buddies’ according to their function (e.g. to manage conflict, to play with or befriend pupils at break and lunch times, to help another to access an activity they could not access without help, to help manage bullying within school). In some schools, children as young as infant age are trained as ‘buddies’ for specific projects in school. ‘Buddy systems’ are becoming common in more junior schools and are usually implemented for specific purposes in secondary schools. As well as helping a pupil with Down syndrome socially and practically, pupils with Down syndrome should also be considered for training as a ‘Buddy’ for others, depending upon the systems in place and the responsibilities entailed.

Creating circles of friends

‘Circles’ of friends is an approach to getting people to think about the importance of having friends in our lives. This approach has been used in many different ways and by many teachers and educational professionals who work with children and adults with disabilities [46]. If a school does not have experience of managing ‘circles’ find an area Educational Psychologist with this as a specialism who can help to get a ‘circle’ underway. Training is available and is worth exploring locally for all pupils in school who are experiencing a degree of social isolation.

Creating opportunities

Unless a Local Education Authority is fully inclusive for all pupils with learning and language disabilities, it is likely that the pupil will need to have opportunities created for them to meet with people with similar disabilities to themselves. We think it is important that these opportunities are provided through adolescence – people with learning disabilities may not choose friends or partners that have similar learning disabilities but this opportunity should be there for them. In adolescence particularly, as young people explore issues that are important for them with their peers, and make their own choices and mistakes, young people with learning disabilities should not be prevented from doing likewise on equal terms with their peers. Currently in the UK, parents of pupils in mainstream secondary schools have the major responsibility for meeting this need – it is difficult for school to set up and manage suitable and supportive social and leisure situations. It need not be impossible though, especially if local special and mainstream schools are working together to develop extracurricular activities through after school clubs. Currently, participation in school sports teams, inter-school tournaments and competitive leagues is more likely in a secondary school for pupils with special educational needs with excellence in sport and leisure activities. Many young people with Down syndrome belong to local youth clubs, sports clubs, dance and drama clubs designed around their needs and skill levels that also include non-disabled peers (often siblings). In our experience, these groups have usually been initiated and developed by parents of young people with learning disabilities, sometimes with financial support from leisure services or social services departments or from voluntary organisations.
Life skills

Social independence

Developing skills for living independently are as important for pupils with Down syndrome as for all other pupils. The aims of the secondary school PSE curriculum are as appropriate as for any other child in a mainstream school. Pupils will need extra help understanding issues that are outside of their life experience - as do some other children. Those pupils that have led full and varied lives and been provided with many opportunities for learning about life by their families are likely to be more knowledgeable. Pupils should not be underestimated on account of having Down syndrome, but should be treated like other pupils, with staff at school understanding that most pupils with Down syndrome will have the same needs for skills in their adult life as others do – they will work, will need to manage their domestic affairs to some degree, will travel independently, will have friends and relationships, and will enjoy and participate in the same range of leisure activities as other people, depending upon their individual preferences. They will need to know how to recognise (and protect themselves) from abuse of all types and know how to seek help and who to seek it from. The needs for good teaching resources, differentiation and clear teaching of life skills are the same as in other subject areas. If it is difficult to develop a pupil’s understanding and confidence in a large group situation then the pupil’s learning may be better supported in a smaller, more specialised group situation.

Like everyone else

When pupils aged 11 and 12 have been due to transfer to secondary education, schools less experienced in the needs of pupils with learning disabilities have occasionally met the request with a response that the pupil needs to learn life skills and they do not know how to teach these. Our advice for staff and parents faced with this initial response would be to target discussion at the practicalities of life skills for all young people aged 11 to 12. What exactly does this pupil need to learn at this point in time that others can do and that he or she can’t? How can we go about teaching him or her? This prevents ‘life skills’ and ‘social skills’ from being a vague area in staff minds with little relevance to the practicalities of life for young people of that age with and without learning disabilities. Schools for pupils with special educational needs can be helpful here (if not directly then through an Educational Psychologist), as all will have a curriculum for developing social and life skills, will expect increasing levels of independence with increasing age and should have administrative procedures to enable the development of cross curricular skills. No less should be expected in a mainstream school, and staff may be surprised at the skills their new pupils already have on entering school. What better opportunity for learning fundamental skills for work in society can there be than the requirement to be in a set place at a certain time with the right books and equipment, repeated many times throughout each day over a five year period on a mainstream secondary school site?

Individual plans

As well as obtaining guidance on life skills based on the life skills of peers of similar age, consideration should be given to the opportunity that each pupil has had to develop life skills. If they have not needed to develop life skills then they might not have done so. It is easy to become overprotective and to continue to provide too much assistance, at school and at home. It is our experience that young people with Down syndrome request independence from their parents as other young people do and it is important to recognise the benefit of increasingly taking charge of your own life for self esteem.

Working with families

The majority of pupils with Down syndrome at transfer to secondary school will be learning to prepare food, make their own packed lunches, make hot drinks, learning to iron and taking responsibility for household chores. They will also be preparing the equipment they need for each day for school and for extracurricular activities, choosing their own clothes and footwear, following fashion in music, T.V. and leisure activities by the age of 11 or 12.
In the community

Enabling the development of life skills outside of the home is more difficult to achieve at this still quite young age and development is typically slower, usually in relation to issues of safety. Young people with Down syndrome may feel restricted here compared with their brothers and sisters or friends, especially towards their mid teen years, depending upon individual circumstances.

Pupils close enough to walk to school without an adult (but with the support of peers) or with good bus routes are at an advantage, and steps can be taken gradually to achieve these skills while offering reassurance to the adults that the pupil is safe. Carrying and using a front door key (even though the home may not be empty on return from school) and short periods of time left at home without an adult should also have been considered by around the age of 14 to 15 for most pupils. It is extremely helpful if the whole family develop more of an interest in using public transport (and walking), know the bus routes and teach the geography of the community in which they live. Being driven about in a car will not teach these skills, although knowing how to ‘phone for, give a location, use and pay for a taxi is an essential life skill.

Handling money

Carrying money, not losing it or giving it away, is often learned in junior school, beginning with small amounts of money. Opportunities for spending money are greater in secondary school, including buying lunch in a canteen. Again, try to use peers or ‘buddies’ to teach these skills, and in life skills teaching relate case studies for how to ask for help or to get yourself out of an overwhelming or ‘uncomfortable’ situation to daily life in school, as well as to the wider world.

Use accredited courses

Accredited courses in key stage 4 that develop life skills and result in a recognised qualification for the pupil at age 16 are likely to be the best way of ensuring that a pupil has been given adequate teaching of life skills through a curriculum. Learning life skills through real life experience requires the co-operation of families and communities as well as a course with learning based at school. Homework, work experience and other work assignments help to develop skills for living with more autonomy and to prepare young people for more vocational learning at Colleges of Further Education, where work in learning life skills will continue.

Transition meetings

While the article has focussed on how to plan for each pupil’s life and education in the secondary school, the planning should start at least a year before a young person is due to move. A Transition meeting is essential and should be attended by all involved, including pupil, family, staff of the current and future schools in order that the secondary school is fully aware of the achievements and needs of the pupil. While academic needs are always discussed, social needs should also be on the agenda. It might be helpful, for example, to recruit a circle of friends who are also moving to the same secondary school to specifically support the student through the transition.

Conclusion

Most pupils in our experience are doing well in secondary schools that have willingly accepted them and that are committed to meeting a wide range of individual educational needs.

Good practice for children with Down syndrome attending secondary schools is developing fast as increasing numbers transfer every year. At present, issues for developing good practice are the same as those for including all pupils with a wide range of individual educational needs in their local secondary schools. The majority of young people with Down syndrome included in mainstream secondary schools need a high level of help and support to function well, and good planning for each individual is a key to success. Good communication within school between all staff and good communication with parents is essential to success. The role of parents has been discussed in relation to a number of the topics discussed and teamwork, recognising parents as full members of the education team, will greatly improve the outcomes for child, family and school.
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Introduction

Over the last twelve months, the author has been collecting data from a sample of over 400 families whose children attend mainstream schools. Their experiences of inclusive education make fascinating reading and illustrate the point made in the Green Paper “Excellence for all children” that provision for children with very similar needs can vary widely from one area of the country to another. From the picture painted by the questionnaire responses, it is now possible to produce guidelines as to what successful inclusive practice should look like.

Models of support

Evidence suggests that a very significant proportion of children with Down syndrome could be placed successfully in a mainstream school. Research data, although still somewhat limited,[1] indicates that such placements lead to academic as well as social gains and increase the chances of the child making local friendships that extend beyond the school day. These facts have lead increasing numbers of parents to seek an inclusive placement for their child.

In some parts of the country[2] over 80% of primary and 50% of secondary aged children are already included, although the picture is very different elsewhere.[3] In all too many Local Education Authorities, parents still have to put up a fight to secure an adequately funded place in their local school. From the current sample of 315 parents who have succeeded in gaining a mainstream place for their child, 29% report difficulties with either the Local Education Authority or the school itself.

While a majority of children with Down syndrome are able to take part in at least some activities with little additional support, maximum benefit will only be obtained if the child has access to a classroom assistant or support teacher for much of their time in school. Further, tasks will need to be modified and adapted to ensure that they are relevant and appropriate.[4]

While there clearly are students for whom only minimal support is required throughout the day, the practice is not generally recommended. All children benefit from some time without direct supervision, enabling them to gain in independence and mix socially with their peer group. On the other hand, it is not possible for a busy class teacher to deliver an appropriately flexible and
differentiated curriculum on their own, without disadvantaging the rest of the class.

A nationwide survey recently carried out by the author indicates that the majority of children with Down syndrome in mainstream schools are supported by a learning support assistant for between 20 and 27 hours a week (Fig.1). Of the children in the survey sample, 58% at primary and 61% at secondary level were largely unsupported at dinner time, at break times and during assembly. A further 25% at primary and 18% at secondary level took part in lessons such as physical education, drama and music without support. However, only 2-3% were unsupported in more academic lessons.

Survey data confirm the view expressed by many parents that the level of support offered by an Local Education Authority has more to do with local policy or the anxieties of schools than with the needs of the individual child. Far too many Local Education Authorities operate a blanket policy which results in all children with Down syndrome being offered a standard package of support. As a consequence, those with lesser needs are frequently over-supported and are, as a direct consequence, less likely to become independent learners. Conversely, those who need more support may have to be transferred to a more specialised setting, against parental wishes, when problems could have been overcome in situ.

What is surprising is that the picture of support at primary and at secondary level is so similar, despite the fact that in most parts of the country the populations differ significantly. Responses from parents suggest that most children with Down syndrome can now find a place in a mainstream primary, as long as the family are persistent and shop around local schools. On the other hand, in many Local Education Authorities, only the most able youngsters are gaining a secondary place.

Several parents in the survey have already accepted the inevitability of special schooling at 11, despite successful mainstream experience at primary level. Nevertheless, where less academically able students have transferred to the secondary sector, they appear to be doing just as well as those with more advanced levels of performance. What seems clear is that 'cognitive ability', whether measured by I.Q. tests or attainment, is a remarkably poor predictor of successful mainstream placement.

Working in a team

In organising support for the student with Down syndrome, the class teacher should aim to:

a) Keep withdrawal to a minimum and give the child access to as much of the normal curriculum as possible.

b) Encourage the child to become an independent learner.

c) Foster co-operative working with other children in the class.

d) Work directly with the children themselves, at least once a week, and ideally daily.

These objectives are best met where class teacher and support staff see themselves as a team, working flexibly to meet the needs of the whole class. As Lorenz notes, a learning support assistant who is always at hand and who prompts the child continually, or intervenes immediately the child is faced with a problem, will inhibit the development of independence.

Far better is a situation where the assistant offers support only when needed and works regularly with other students who require help. Although some parents become very agitated when they find some of their child's hours being used to assist other children, this approach is likely to be far more beneficial in the long term than continual one to one support. It frees the class teacher to work directly with the child and gives the child opportunities to work with other people.
In some schools, particularly in the secondary sector, young people with Down syndrome are increasingly being supported by more than one assistant. This can work well where communication is good and support staff are placed in settings where their particular skills can be used to best effect. This approach, while still relatively uncommon, has several advantages:

a) it avoids the unnaturally close relationship which sometimes develops between child and assistant,

b) it allows cover to be arranged more readily if one assistant is ill or on a training course, and

c) it avoids the trauma caused to a child whose support assistant leaves.

In the author's survey, virtually all primary aged pupils were being supported by one assistant. However, in the secondary sector, 32% had two or three assistants, while 19% were being supported by different assistants in different subject areas. Lee and Henkhuzens, in their study of ten inclusive secondary schools from five different Local Education Authorities,[7] recommended the attachment of support assistants to subject departments as:

a) It enables learning support assistants to become familiar with the subject area and the way in which each topic will be approached.

b) It allows the assistants to feel more confident in their ability to support students appropriately, particularly where it is possible to place assistants in subject areas where they already have confidence, expertise or interest.

c) It increases opportunities for assistants and subject staff to work together to produce a bank of appropriate materials.

The role of support staff

When support staff are used, whether teachers or support assistants, it is important that all concerned are clear about their role.[8] They should be there, primarily, to assist the child, although they also have a part to play in supporting the class or subject teacher. Many of the roles can be carried out equally well by teachers or support assistants. However, schools must ensure that staff without teaching qualifications are not asked to plan work or teach students on a withdrawal basis unless they are under the direct supervision of the class teacher. On the other hand, using teachers for general in-class support may be a poor use of scarce resources.[9]

One key aim of support, particularly at secondary level, must be to increase students' independence and progressively reduce their need for adult assistance. An adult accompanying a primary aged child around the school building is accepted as fairly normal practice. However, adults do not generally follow secondary aged students from one class to the next. Where support is required, this is best provided by peers. By encouraging other students to become involved it may be possible to overcome some of the problems of social isolation experienced by many young people with Down syndrome as they approach adolescence.

Involving the class teacher

In primary schools where there is more than one child receiving support, changing the support assistant, as well as the teacher, when the child moves classes can be a useful strategy, although one that is rarely used. Not only does this encourage the new teacher to take a personal interest in the child with Down syndrome, instead of relying on the assistant who already knows the child, but it prevents assistant and child becoming too close.

Where a learning support assistant is able to remain with the same teacher, rather than the same child, joint working practices can be developed over time to the benefit of all. However, in many schools this is not possible as their funding only permits them to employ one support assistant. Nevertheless, there is still a lot that can be done to prevent difficulties, when a school is aware of the potential pitfalls of over-dependence.

An assistant who has worked almost exclusively with the same child for a long time may be reluctant to let go and may be unwilling to work with other children in the class, even if this is in the target child's best interest. While parents and pro-
Professionals should undoubtedly be fighting to maintain an adequate level of support for every child with Down syndrome, they should be equally vigilant and object just as strongly where children are being over-supported.

According to parents, in more than half of the schools sampled, the child's support assistant sits next to them for most of the time, occasionally or never working with other children in the class (Fig. 2). Survey data indicate that in 28% of cases, primary aged children with Down syndrome are taught by their class teacher less than once a week. In the secondary sector this rises to 53%, with subject teachers all too often having little direct involvement in the child's educational programme (Fig. 3).

At primary level, almost all direct teaching is carried out by support assistants. Yet we know that over half the learning support assistants involved have no formal qualifications, nor have they received any training in the teaching of children with Down syndrome. At secondary level students are likely to be taught either by a support assistant or by a support teacher without particular subject expertise. Hopefully, as teachers get more confident in teaching students with Down syndrome and learn to work more flexibly with support staff, the picture will change.

Support for support staff

Most schools, quite rightly, emphasise the need to provide an adequate level of support for the child. However, they often fail to recognise or acknowledge the support needs of their staff. Questionnaire responses suggest that 69% of the primary and 81% of the secondary schools in the survey receive no input from an Local Education Authority advisory service. Of those that do, only 11% of primary and 7% of secondary schools see an advisory teacher more than once a term.

Even where outside help is available, parents and teachers should insist that time is provided for support assistants and teachers to plan their work. Special Educational Needs Co-ordinators, whose responsibility it is to manage the support staff, should ensure that they are given sufficient time away from their normal teaching duties to carry out this essential function.

Although non-contact time is provided in over half of secondary schools, when teachers and assistants can discuss their respective roles and responsibilities, only a third of primary support assistants are given paid planning time. Undoubtedly some will stay behind after school, or give up their lunch break, to discuss the needs of the children they support. However, it seems unreasonable for schools to take advantage of the goodwill of such poorly paid staff. The solution lies in the hands of Local Education Authorities who should recognise the importance of planning and build it into the provision on the child's statement.

Accessing the curriculum

In the primary school, there is generally little choice for the class teacher, other than to involve the child in normal classroom activities or alternatively, to ask the support assistant to work with them individually or in a small group. At secondary level there are many more possible options. Survey findings suggest that most secondary aged students with Down syndrome are taught in mixed ability classes for at least part of the week,
with or without additional support, and in lower sets or withdrawal groups for the remaining lessons.

Over a third of the students receive some additional in-class support from a learning support teacher in maths or English, while around half are withdrawn for individual or small group help at least once a week. Although most students with Down syndrome spend some time in bottom sets, one young man has been placed in the third of four sets, to avoid the disaffected and troublesome pupils often found in lower achieving groups. This is particularly pertinent for students with Down syndrome who frequently mimic the behaviour of their peers.

As Lee and Henkhuzens [7] note:

If you have a group of pupils with learning difficulties (and maybe associated behavioural difficulties) all together, there are no positive role models available, the teacher may be the only source of ideas and information, and the group may be perceived as difficult to teach.

Support from speech and language therapy services is also reduced significantly at secondary transfer, with 68% of secondary students receiving no speech therapy input as compared with 33% of primary aged students. However, even at primary level, only 29% of children see a therapist more than once a term, despite the major language problems experienced by most children with Down syndrome and the acknowledged need for support staff to be trained and supported in their language development work.

None of the primary aged students in the study were disapplied from the National Curriculum, although a small percentage of those in secondary schools were disapplied from modern languages. In some schools, the provision of a Learning Support option at Key Stage 4, allows additional time to be given to basic skills or complementary studies. In others, students in their final years are provided with an individualised curriculum containing both academic and vocational elements.

Conclusions

Data from over 300 questionnaires, followed up by discussions with parents and teachers, show quite clearly that successful inclusive education for many children with Down syndrome is a reality both at primary and at secondary level. Yet for
Making inclusion work for children with Down syndrome

others, mainstream placement appears to be offering little in terms of skilled teaching or peer group interaction. While adequate levels of resourcing are clearly important, greater attention needs to be focussed on the way in which support is used.

The key factors for successful inclusion appear to be:

1. A positive attitude of the school as a whole to the disabled child.

2. A flexible approach to the use of support staff.

3. Ownership by the class teacher of the child's learning programme.

4. Good communication between the school and the parents.

5. Support for the school from Local Education Authority services.

If these are in place, there is no reason why the majority of children with Down syndrome could not attend their local school and benefit both socially and academically from an inclusive placement both at primary and at secondary level.

References


Further reading

Experiences of inclusion for Children with Down's Syndrome, a report detailing the research upon which this article is based, is available from The Down's Syndrome Association, 155 Mitcham Road, London, SW17 9PG, England

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A common concern for families of children with Down syndrome is weight management. Since many people have a stereotypical opinion that people with Down syndrome are obese, weight management is often a source of worry.

Preventing obesity through an active lifestyle, nutrition education, and emotional support from family and friends is the ideal answer. In a perfect world, this begins in early childhood. Great idea, but not always easy to put into practice. This is part one of a series of three articles promoting sound weight management and food-related habits in: 1) Early Childhood, 2) School Age and Adolescence, and 3) Adults: At Home and in the Community.

Recent research suggests that children with Down syndrome have a lowered resting metabolic rate than their friends who are the same age. This probably isn’t going to change as they get older. The same research showed that children with Down syndrome are just as active as other kids their age during the course of the day. Additionally researchers found that, like other children their age, when making their food choices without adult direction, children with Down syndrome chose foods that met their overall calorie needs and were nutritionally balanced over time. However, because their overall calorie needs were lower, the total amount of food chosen was less. This means they may be at risk for vitamin and mineral deficiencies. These deficiencies are best met by supplementing with a standard over-the-counter multivitamin rather than over-management of food choices.

Clinically, there are different categories to describe a child’s weight:

<table>
<thead>
<tr>
<th>Category</th>
<th>Definition</th>
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</thead>
<tbody>
<tr>
<td>Appropriate</td>
<td>within 90-110% of desired weight</td>
</tr>
<tr>
<td>Overweight</td>
<td>111-120% of desired weight</td>
</tr>
<tr>
<td>Obese</td>
<td>&gt; 120% of desired weight</td>
</tr>
<tr>
<td>Morbidly obese</td>
<td>&gt; 200% of desired weight</td>
</tr>
</tbody>
</table>

Chances are parents already have an idea where their child fits on the scale. If not, adapted growth charts for children are widely available in books like Babies with Down Syndrome — A New Parent’s Guide (p. 105-108),[3] or on the World Wide Web.[a] Beyond the 95th percentile, an educated guess of where a child fits is needed.

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A focused guess is probably sufficient. Also, if a child is beyond the 95th percentile for weight, that does not mean they are above their desired weight. For instance a child can be off those charts for both height and weight, and not be overweight. The most important use of growth charts, especially in the younger years is to look for unexpected changes in how children are following the growth curve. An unexpected drop from over the 95th percentile to the 50th percentile is just as worrisome as an unexpected jump from the 50th percentile to the 95th percentile.

It is difficult to hear these medical categorizations attributed to a child because of the emotions we feel when we hear the terms “obese” and “morbidly obese.” Remember, they are simply words that describe a condition. The real question is “What to do about it?”

As with everything, it is best to begin at the beginning. First, check with your pediatrician to eliminate any medical reasons that might cause a child to be overweight such as a low thyroid level. If there are no medical concerns, then the child is usually overweight or obese because there is an imbalance to the energy equation. The amount of energy taken in is greater than the amount of energy going out. There are three ways to begin to balance this equation:

- Increase energy-out through activity,
- Decrease energy-in by limiting calories, or
- Both increase energy-out through activity and decrease energy-in by limiting calories.

A focus on calories alone is not only risky for children’s health, but it focuses too heavily on food. All children have great vitamin, mineral, protein, carbohydrate, and energy needs while they are growing. Limiting calories may cause children to get too few of what they need to develop well. An abnormal focus on food can also become an obsession over time. However, increasing activity not only burns more calories, but it has long-lasting health benefits such as increased muscle tone, increased metabolism, decreased resting heart rate, better sleep, and an overall sense of well-being. Therefore, the best approach is to focus on healthy food habits to fuel the body and to promote activity.

When working with overweight children with and without Down syndrome, the goal is to maintain the child’s current weight while they grow rather than losing pounds. As they grow, their height will be more appropriate for their weight. With this in mind, let’s look at some of the more important concerns in early childhood.

Ellyn Satter, a registered dietitian and certified social worker, has done significant work and research into the food choices, attitudes, and the feeding relationship between adults and children.[4] Her research found that over time, when taught to listen to their body regarding hunger and food, children chose foods that met their nutritional needs for calories and vitamins and minerals over time, just as the children with Down syndrome did in the study discussed earlier. The trouble is, parents have preconceived ideas about what, when, and how much a child should eat. Her recommendation is to define the roles of the feeding relationship in the following way:

- Adults are responsible for what is presented to eat, where it is presented, and when it is offered.
- Children are responsible for how much and even whether they eat the food offered.

The only change to this philosophy for children with Down syndrome is the addition of an over-the-counter multivitamin to accommodate for potential micronutrient deficiencies. This philosophy is particularly helpful when dealing with overweight children or changing food habits. As the “food battle” begins, parents have a rule to follow rather than a situation to control.

The early childhood years (ages 2-6) are loaded with challenges for children with Down syndrome. Some transition from being land rovers (crawling) to running (what happened to walking?). Some will transition from using sign language as their primary communication tool to verbal approximations. Others will begin working with pictures and voice output devices. Most will discover the novelty of friends, experience their first preschool, and, to most parents chagrin, dis-
cover the word “MINE!” And they will all learn how to wrap Mom and Dad lovingly, but deviously, around their little finger.

What a busy life they lead. Regardless of their weight, the most important thing parents can do during this time and throughout their child’s life that will affect their weight is to build their self-confidence and self-esteem. For the child who is overweight, this may be the most effective tool a parent has to offer. This is when the responsibilities of the feeding relationship mentioned above become an essential tool. The responsibility of parents is to feed children lovingly and responsibly. It is not to monitor how many servings of vegetables are eaten in a day, whether or not they cleaned their plate, or if they ate brownies over at their friend’s house. It is the parent’s responsibility to provide a structure for food choices and eating habits that is healthy, consistent, and without judgment.

Some ways to create this structure include:

- **Providing scheduled meal and snack times.** Children need to know that food is going to be provided. If meal and snack times are inconsistent, they may hoard food at mealtime or snack time because they worry about being hungry.

- **Limit eating to a few areas of the house.** This keeps everyone from eating in front of the TV, and discourages grazing (constantly eating throughout the day). It also keeps the house cleaner!

Let kids help prepare meals and snacks. Meal and snack preparation are the perfect time for some fun learning experiences. Cooking provides many opportunities for grouping (group foods by size, colour, or type), one-to-one correspondence (setting the table), and promotes lots of fine motor activities. Picking up nuts to put in the bread machine is just as much fun as putting Fruit Loops in an egg carton and the result is bread for dinner! The more comfortable kids with Down syndrome are around food, the more competent they will be at making their own food choices later in life.

Do not use food as a reward. This can be difficult for parents of kids with Down syndrome because of all the people involved in their lives. Discuss how to handle rewards without using food with school personnel, private therapists, and babysitters. If a child learns that certain foods are special by receiving them as a reward for good work, they will likely carry that into their adulthood.

Do not offer food unnecessarily. If a child falls off the swing at the playground or has his feelings hurt by a playmate, do not comfort him with freshly baked brownies. Also, do not offer high sugar drinks like soda and juice to quench thirst when water will do. Calories add up quickly when you drink apple juice whenever you’re thirsty!

Remember there are some situations that are nutritional “goners.” Sleepovers at Grandma’s house, holiday gatherings, and birthday parties are situations where every child eats differently. If a child is behaving like all the other kids and the only reason to step in is his weight, don’t do it. Let him be a child. Food is one of the great social equalisers. Kids with Down syndrome need those moments to build strong friendships that will last when they get to elementary school.

In addition to these food-related goals, it is important to be active as a family. Find games and activities that can be done as a group such as tag, going for walks, swimming, or riding trikes and bikes. Being an active family will introduce activity to a child’s life as a fun thing to do. Although activity plays an important role in normal eating patterns and overall good health, at this age, it is not imperative. For the overweight child with Down syndrome, the relationships that are built in the process are the most important part of the activity. This is another way to build self-confidence and self-esteem.

The most important thing to remember is that any changes made must be gradual, long-term, and for the entire family. Young children with Down syndrome who are overweight do not need to be put on diets. They do not need their food micro-managed. They need parents who set boundaries and provide the security of structure regarding food. They will be most effective at managing their food choices and many other choices in life if they believe in themselves and their abilities. It is in these early years that we, as parents, can build a
strong foundation for all the challenges that lie ahead, including food.

References


Further reading and resources

Nutrition books and activities for the early childhood years


*Learning to Set the Table Placemats*: Set of 4 and Matching Dish Set: Set of 4. A set of placemats with outlines for where dishes go in a place-setting for a meal. The Dish set exactly matches the outline on the placemats. Available from Lakeshore Learning Materials. +1 800/421 5354

*Vegetable Lotto*. A wooden lotto game for various vegetables. Available from Nasco Nutrition Teaching Aids. 4825 Stoddard Rd., Modesto, CA 95356-9318. 209/545-1600. Web: http://www.nascofa.com e-mail: info@nascofa.com

*Yummy 5-A-Day Fruit and Vegetable Game*. A Lotto Game. Available from Nasco Nutrition Teaching Aids. 4825 Stoddard Rd., Modesto, CA 95356-9318. 209/545-1600. Web: http://www.nascofa.com e-mail: info@nascofa.com

*Classroom Cooking From A-Z*. An entire set of activities and tools (alphabet cookie cutters, measuring cups, and so on) for edible activities that teach the alphabet. Includes a recipe box with a recipe for every letter of the alphabet. Available from Lakeshore Learning Materials. +1 800/421 5354

The author

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WEIGHT MANAGEMENT IN DOWN SYNDROME — THE SCHOOL AGE AND ADOLESCENT YEARS

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Summary — This article is the second of a series of three articles promoting sound weight management and food-related habits. It focuses on developing appropriate diets and physical activities during school and adolescent years.

Keywords — Down syndrome, weight management, health, school-aged children, adolescents

Introduction

The first article in this series focused on weight management in the early childhood years. The emphasis during those years is on establishing the feeding relationship and setting boundaries that promote a healthy lifestyle. This article focuses broadly on the school age and adolescent years.

Parents of children with Down syndrome have a multitude of hopes and dreams for their children as adults including living independently, cooking healthy meals, being active, and making smart lifestyle choices. As parents, we want our kids to have it all. In the past, many of the skills needed to accomplish these goals were taught in special education or life-skills classes. For instance, a unit in a life-skills course often covers grocery shopping, menu planning, some cooking skills, and leisure plans. However, as more children are included in regular education classrooms, these skills are not routinely taught. Children with Down syndrome will receive the same quick, fragmented nutrition education as other students, leaving them to try to decode confusing and often inaccurate messages from commercials, movies, and their friends.

In a perfect world, successful and realistic weight management for persons with Down syndrome is preventive in nature. Research and observation show that children with Down syndrome are at a greater risk to become obese. Their bodies use fewer calories to do the same activities as their same-age peers. Preventing obesity or limiting weight gain through the foundation of a healthy lifestyle, is the only reasonable option. However, weight management and healthy lifestyles do not happen magically; they are learned. That means that this foundation to a healthy lifestyle must be strategically presented in a way that is meaningful and lasting.

Fortunately families are not limited to what occurs in the classroom or on the playground to encourage healthy lifestyles. Parents can make a significant difference in the lives of everyone in the family by creating an environment that promotes healthy lifestyles. Some key elements to consider are:

An attitude of complete acceptance. This is especially important if your child is overweight. Do not be obsessed with your child’s weight, food choices, or the negative consequences of being overweight. Children with Down syndrome need
to know that relationships are not contingent on how much they weigh or what they eat. It is important to discuss your concerns without becoming "the food police."

Model the expected behavior. Children with Down syndrome learn by watching those around them. The most powerful tool available to parents to influence children's choices is being healthy and active themselves.

Allow your child to make choices. Do not ignore your child's food preferences in the pursuit of good nutrition. Provide an array of choices that have something everyone likes along with new foods to experiment with. Create a win-win situation at meal-time as often as possible. The more a child with Down syndrome feels they are in control of successful situations, the more they will continue to make similar choices when on their own.

Create opportunities for successful independence. Whenever possible, set up situations that allow for independence in food and activity.

With these attitudes and strategies in mind, there are countless areas parents can work on to teach the skills and build the confidence a child with Down syndrome needs to independently make smart choices. The examples in this article focus on three areas: snack choices, menu writing, and routine activity schedules.

### Snack Choices & Menu Writing

Similar to the early childhood years, school-age children and adolescents with Down syndrome (ages 7-16) need the security of boundaries regarding food choices. These boundaries, established by the feeding relationship, create opportunities for success and independence.

Building confidence and independence in food choices is best done through practice, the earlier the better. Start by creating a list of each person's favorite foods (see table 1). This list, arranged by food groups, becomes a tool for structuring menu planning and snack choices. Update the list periodically to allow for changing tastes and fads. There are a variety of ways to use this information that provide practice for making smart food choices.

Set up a snack choice system. Using a collection of foods from the family favorites list, provide an array of healthy and not-so-healthy snacks (no one is healthy all the time). After school, your child may choose one snack choice. Take time to discuss the available choices, food groups, and the appropriate serving sizes with her.

Encourage appropriate serving sizes and food budgeting. Stock the snack shelf or drawer with a one-week supply. Be available to discuss your child's choice at first, slowly lessening your involvement. If the snacks run out before the end of the week, she must wait for the snack options.

<table>
<thead>
<tr>
<th>Breakfast</th>
<th>Lunch &amp; Dinner</th>
<th>Fruits</th>
<th>Vegetables</th>
<th>Bread, Cereal, &amp; Grain</th>
<th>Snacks &amp; Sometimes Foods</th>
</tr>
</thead>
<tbody>
<tr>
<td>pancakes</td>
<td>meatballs</td>
<td>pears (canned)</td>
<td>raw:</td>
<td>bagels</td>
<td>pretzels</td>
</tr>
<tr>
<td>french toast</td>
<td>pizza</td>
<td>banana</td>
<td>broccoli</td>
<td>dumplings</td>
<td>popcorn</td>
</tr>
<tr>
<td>corn flakes</td>
<td>stir fry</td>
<td>grapes</td>
<td>carrots</td>
<td>stuffing</td>
<td>popcorn cakes</td>
</tr>
<tr>
<td>muffins</td>
<td>mac &amp; cheese</td>
<td>oranges</td>
<td>celery</td>
<td>homemade rolls</td>
<td>chips</td>
</tr>
<tr>
<td>toast</td>
<td>PB &amp; J</td>
<td>star fruit</td>
<td>jicama</td>
<td>french bread</td>
<td>nachos</td>
</tr>
<tr>
<td>hot chocolate</td>
<td>soup</td>
<td>Kiwi</td>
<td>peas</td>
<td>barley</td>
<td>ice cream</td>
</tr>
<tr>
<td>orange Juice</td>
<td>Lasagna</td>
<td>berries</td>
<td>snow peas cooked:</td>
<td>biscuits</td>
<td>reg. soda</td>
</tr>
<tr>
<td></td>
<td>Chili</td>
<td></td>
<td>broccoli</td>
<td></td>
<td>granola bars</td>
</tr>
<tr>
<td></td>
<td>Lentils</td>
<td></td>
<td>corn</td>
<td></td>
<td>candy</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>gr. beans</td>
<td></td>
<td>cookies</td>
</tr>
</tbody>
</table>

Table 1: Family Favorite Worksheet
to be replaced the next week.

Let your child help create the snack menu from the list of family favorites. Highlight the foods on the list that are snack foods. Be sure to add new foods to the list of possibilities. Have her choose a specific number of snack foods from each food group to emphasize the importance of balance in food choices.

Involve older children in menu planning. This is usually harder on the parents than the kids. A nutritionally balanced meal includes at least three of the five food groups (the "sometimes" group is excluded) from the food guide pyramid. For instance, a meat and bean burrito with a tossed salad uses the grain, vegetable and meat groups. It is nutritionally balanced. Remind your child to include foods equally from other family members' favorites, not just their own.

Focussing discussions on an understanding of food groups and using a variety of foods for good health encourages wise food choices. The Food Guide Pyramid is a useful teaching tool for promoting balance, encouraging independence, and avoiding the "good food vs. bad food" theme. There are also many inexpensive nutrition-related games available that may be helpful.

Routine Activity

From the parent point of view, letting kids be inactive is the easiest thing to do. It requires little planning, time, or money. After a long day of work, dealing with friends and family, pulling together meals, and completing household chores, the easiest choice is to let kids entertain themselves. Most likely, they will fill up their time with television, computer games, homework, and free time.

However, children with Down syndrome need to be taught how to use their time in a constructive and healthful manner. After school activities, team sports, and Special Olympics can fill some of their time, but it is limited to the season and other schedules. One solution is to build an after school

Kids in After-School Care

**Transition time:** hang up coats, find classroom, and so on. Many programs have a circle or reading time to begin the afternoon.

**Snack:** Investigate the facility's menu. If the snack choices are not acceptable, do not single your child out by demanding special snacks. Offer to work with them or make donations to improve the menu for all the children.

**Physical Activity:** Be direct with the staff about your expectations for your child. Sending everyone out to the playground for free play is easy, but the only aerobic activity is running between equipment. Talk to the staff about encouraging games that will be fun for everyone: dancing, organized tag, and other group activities.

**Homework:** Find a study buddy for your child. If your child is younger, ask if a child from an older age group could read, color, or play educational games with your child. Send nutrition-related games and activities that can be copied for everyone.

**Going home:** Time to share the events of the day.

**Transition time:** Allow for a few minutes of free time to talk with you, listen to music, put things away, and so on.

**Chores:** For kids in after school care, the most helpful chores are probably related to meal preparation and clean up.

Limit television to one hour each day.

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**Table 2. After-school schedule - Children who come straight home**

| **Arrive home:** | Time to go through backpacks, hang up coats, and share the events of the day. | (10-20 minutes) |
| **Transition time:** | A few minutes to rest, listen to music, or talk. | (10 minutes) |
| **Snack** | (10-20 minutes) |
| **Physical Activity:** | Time for some exercise. Kids have been in class all day and need to burn off some energy. Some suggestions are playing ball, tag, indoor kickball with balloons, and dancing. | (30-45 minutes) |
| **Homework:** | Kids can start homework while Dinner's being prepared. If your child is too young for homework, play a lotto game, color, or read a book together. This is a good place to work in menu planning or nutrition-related games. | (as long as it takes) |
| **Chores:** | There's a lot to learn and many calories to burn through household duties. Teach new chores together. Some suggestions are: setting the dinner table, after dinner clean-up, folding laundry, and vacuuming. Teenagers who are sometimes on their own will need a written schedule with expectations and suggestions. | Limit television to one hour each day. |

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**Table 3. After-school schedule - Children in after-school care.**
routine that has structure and limits sedentary activity. These after school routines provide a framework that helps children use time wisely, discourages long periods of sedentary activity (watching television or playing computer games), and encourages families to spend time together.

For parents of children with Down syndrome, these after school routines will require planning and time by parents and caregivers. Careful thought must be given to providing support and encouragement. Children who go home directly after school (see table 2) will have slightly different options than children who go to after school care (see table 3). It may be helpful for parents of children who come directly home to hire a high school or college student to help once a system is in place. Weekends are a good time for activities that everyone can be involved in: hiking, walking, biking, and so on.

All of these suggestions for food and activity choices look wonderful on paper. Parents of kids with Down syndrome lead busy and sometimes stress-filled lives as they deal with the usual parenting concerns along with private therapies and managing their child’s I.E.P.

However, those I.E.P. meetings come in handy. As you plan for changes within your family, take advantage of the information you have learned from teachers and therapists at I.E.P. meetings and private therapy. For instance, if your child needs a picture system, many of the menu planning and food choice ideas can be done with simple drawings. Or, if your child needs some cues for setting the table, there are placemats that have the position for each item printed on them or you can mark where things go on the table with masking tape.

Most important, focus on the improvements everyone has made rather than the imperfections of food and activity choices. Creating a healthy lifestyle does not mean a perfect lifestyle. Continue building on your successes and the successes of your family one-step at a time. Set goals for changes that are important, yet small and easy to accomplish. Remember to reward yourself and your children in ways that are supportive of a healthy and active lifestyle, such as exercise clothes, books, or music. Most importantly keep in mind that healthy lifestyles don’t just happen; they are taught. If kids with Down syndrome learn healthy habits in the school age and adolescent years, there will be less to re-learn as they prepare to live on their own. Every step, no matter how small, is a step toward building healthy habits and healthier futures.

References

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Introduction

Weight management is something that everyone would benefit from understanding early in life. The first article in this three-part series looked at the importance of the feeding relationship to a healthy lifestyle and early eating habits for young children with Down syndrome. The second article looked at concerns of the school-age and adolescent years: carefully building independence and modeling the habits that shape a healthy attitude toward food and activity. This article, the last of the series, continues to focus on issues that are relevant to weight management and Down syndrome, with an emphasis on concerns that arise in adulthood. For adults with Down syndrome, weight management involves more than the physical changes of maturity. It is a complex mix of community involvement, friendships, daily routines, living situations, activity, and food choices along with the physical challenges of age. This article will explore many of these influences and how we, as parents, family, and support people can encourage adults with Down syndrome toward a healthy lifestyle.

The effects of metabolism

Research suggests that children with Down syndrome have a lower basal metabolic rate (BMR) than their same-aged peers. BMR is the rate a person burns calories for fuel when completely at rest-or sleeping. As a result, a child with Down syndrome uses fewer calories while they are asleep and also throughout the day.1,2 In addition, adults with Down syndrome (ages 18-20) have finished growing and require fewer calories than they did as a child. If eating or exercise habits do not change to compensate for this decrease in energy requirements, the energy equation quickly becomes unequal with Calories in outweighing Calories out.

Slowing or stopping the rate of weight gain

If your child is still gaining weight consistently, focus on stopping or slowing that upward trend. This is a quick fix, however, and only meant as a detour while the two of you consider other factors and make changes. To do this, it is important that your adult child understands and shares your concern regarding his weight gain and overall health.
Without him on your team, you will be waging a losing battle. Working together, success is far more likely.

The first thing to do is to visit with your family doctor to rule out any medical causes of weight gain such as hypothyroidism. Be certain to ask if there are any physical limitations to be considered if your child decides to increase his physical activity. Once the physician has given you the "green light" for lifestyle changes, your child and you can begin to create a plan together for a healthy lifestyle.

To slow or stop weight gain, begin by choosing an area of the energy equation to modify. Keep in mind you’re not trying to accomplish weight loss at this time. Focus on beginning healthful habits that your adult child is willing to do. Some areas to consider are:

- Increasing activities such as walking, and using stairs,
- Confining eating to designated areas,
- Balancing meals,
- Planning snacks rather than eating uncontrolled, and
- Menu planning.

Usually small changes in any one of these areas will slow or stop consistent weight gain. Do not try to create perfect habits. Accept and encourage any changes, no matter how small, your child is willing to make. Many times the most effective initial change to encourage is an increase in activity. A walk around the block for each 30 minutes of television watched is very effective in our culture. Increasing activity has some other health benefits that may spill over to other areas as well. They include, but are not limited to:

- An increase in muscle mass and muscle strength, and
- A decrease in blood pressure.

Once you have both agreed on a plan to slow or stop weight gain, it is time to move on to the next step: evaluating and shaping opportunities for choice and control regarding food and activity.

**Making lifestyle changes - who decides?**

In the past, when a medical intervention was needed for a person with Down syndrome, a professional stepped in to create a plan or a treatment to correct the situation. Basically, weight management was done to them. This can happen in any living situation, and still does.(3,4) Many well-meaning parents and professionals deny adults with Down syndrome control over their food choices by mandating a strict menu, a dietary restriction, or an exercise regime. This rarely leads to long-term success in weight management. In fact, if the person with Down syndrome is not involved in the decision-making process, it might lead to rebellious choices such as covert eating or uncontrolled eating at social gatherings in an effort to regain control of food choices. For this reason, it is wise to avoid "diets" and "treatment plans" by involving the person with Down syndrome in discussions about weight and overall health promotion and letting them take the lead in the decision-making process.

One way to begin identifying potential areas for change is to evaluate the living situation of your adult child and try to create opportunities for choices and control that include healthy options as much as possible.

**In Group Settings**

Meet with the owner or manager of the living group to discuss your concerns. Consider asking the following questions:

- Are the people who live in the group home involved in menu planning? Cooking? Shopping?
Does the menu structure allow for more than one entrée and a variety of side dishes for each meal?

Does the support staff model and encourage healthy choices?

Is there a variety of healthy foods available for snack choices?

Are opportunities for physical activity such as low-impact aerobics, walking, or biking available? How often?

Once you have asked these questions, share the options with your child. Emphasize that he is in control of his options by pointing out the areas he has choices to make.

Living at home with family

Ask yourself this question: Is better health a priority for everyone who lives in your home? It is important to send a consistent message regarding healthy habits to your child with Down syndrome. If it is, gather as a family to discuss what changes each person would like to make for a healthy lifestyle. Most families do not have weekly menus, but now would be a good time to begin using them.

Together, create menus for meals and snack choices. Most meals (breakfast and lunch in particular) can be written to include different options for varying needs in the family. The point of the menu is to ensure that only foods the family agrees upon are in the home. Involve your adult child in cooking and shopping activities.

Supported and independent living

Menus are very helpful for adults with Down syndrome living independently. However, they must be written by the self-advocate. Encourage using a variety of foods in menu planning. When cooking for one or two, or when cooking is a lot of work, it is easy to only make a few things that are favorites like macaroni and cheese, peanut butter sandwiches, and other easy-to-prepare dishes.

One way to encourage experimentation with new recipes is to plan a dinner together once a month. The theme of the meal is trying new recipes. It is easier to try something new with a companion. Together, you can choose a new recipe to try, create the menu for the night, shop for what is needed for the recipe, provide support to your child learning the recipe, and live the adventure of tasting this meal together. If it is good, then begin adding it to the menu once a month.

In this living situation, parents and support people have the least influence or control over what actually happens. However, menu planning, when done by the person with Down syndrome with support, only as needed, not only provides structure, but also makes shopping and budgeting much easier because it is planned in advance. By planning ahead using a menu, the foods needed for recipes are on the shopping list, and therefore available when it’s time to cook them. Menu planning is the best defense against developing the habit of standing in front of the cupboards trying to decide what to cook. Cupboard-side menu planning typically leads to fast foods or skipped meals.

Nutrition guidelines - a “Rule of Thumb” approach

As a parent or support person, it is helpful to have an idea of the most basic concepts for healthy eating. Use these guidelines to assist you:

- Plan for and eat three meals a day.
- Time those meals so they are not more than 5 hours apart. If meals need to be longer than 5 hours apart due to work or school schedules, plan for a snack.
- Each meal should consist of 3 out of the 5 food groups for overall balance.
- Each planned snack should consist of 2 out of the 5 food groups for overall balance.
- Don’t go out of your way to plan for the “sometimes/others” group (the sixth group at the top of the pyramid). They seem to find their way into menus on their own.
• Encourage your child to take one-half of the portion they feel like eating. When that is gone, have them set the timer for 15 minutes. If they are still hungry after the timer goes off, then seconds are in order.

These guidelines will ensure overall nutritional balance throughout the day while leaving room for food preferences and individual decisions. Teaching adults with (or without) Down syndrome to choose within these parameters because they are healthy for everyone will promote healthful choices without feeling restrictive. If you are worried about the nutrients that may be missed by food choices, an over-the-counter vitamin will take care of any nutrients that are missed.

Activity & friendships: - essential pieces of the puzzle

The last area to consider, though just as important, is activity. What kind of opportunities does the adult with Down syndrome have to create new friendships, socialize with old friends, and participate in recreational activities? In a recent study, researchers found a correlation between friendships and opportunities for recreation and the body mass index (BMI) of adults with Down syndrome.[5] BMI is a measurement used to assess body weight and health risks using body weight and body fat.[6] This study suggests that for adults with Down syndrome, friendships and social interactions have a more consistent and direct effect on BMI than diet and exercise. This is a very strong message. It suggests that better health and weight management for adults with Down syndrome must include the element of friendships and social recreation in addition to the usual healthy lifestyle choices (eating and exercise) to be successful. Friendships and opportunities for recreation are “inextricably linked” to overall health.

As a dietitian and mother of a child with Down syndrome, I see this as an opportunity to create some healthful options for people with and without Down syndrome now and in the future. Once again, it will require advocacy by parents, parent groups, and professionals to be successful. Some places to consider beginning include:

• Joining walking or Volksmarch clubs, especially those associated with a hospital,
• Offering community aerobic classes at the group home or nursing home,
• Doing aerobic tapes with friends at home or in apartments,
• Joining local health clubs and buying YMCA memberships,
• Hiring a personal trainer at a health club or YMCA to work with a two or three adults with Down syndrome as a small group,
• Joining a hiking group for beginners,
• Creating an exercise buddy system with friends and relatives, or
• Walking the dog with a group of dog owners.

Although it is important to promote healthy eating habits, the nutrition and activity pieces to the puzzle of weight management for adults with Down syndrome are relatively easy. The harder pieces to fit into place are the ones we cannot dictate or force: choosing to eat wisely, choosing to be active, and cultivating the friendships that complete the puzzle of a fulfilling and healthy life for our children. The best we can do is to ensure the tools for a healthy lifestyle are taught, available, and encouraged in a positive way, and encourage friendships and recreation throughout their lives.

References


7. BoardMaker icons used with permission of Mayer-Johnson, Co., P.O. Box 1579, Solana Beach, CA 9207507579.619-550-0084.

The author

Joan E. Medlen, R.D. Is a registered dietitian and mother of two boys, one of whom has Down syndrome. Joan is a private consultant and an editor. She resides with her family in Portland, Oregon.
Introduction

The area of sexuality is still very much a taboo subject when it comes to the experience of sexuality for people with an intellectual disability. It is worth exploring just what some of the myths and taboos are regarding sexuality and disability, to gain some insight into why it remains a topic of such denial and/or heated debate. Many people believe that a person with an intellectual disability has no sexual thoughts, needs or desires; that the disability itself impairs sexuality and that teaching people about sex will only encourage them to act out sexually and inappropriately. Others believe that a person with an intellectual disability, if displaying sexual needs or desires, is deviant and therefore a threat to society. We need to ask ourselves what effect these myths have within the community and how our own unexamined attitudes may actually support them. While they are gradually being eroded by the sexuality education programs now being offered to disability workers and to service users themselves, people with intellectual disability are still bearing the brunt of community adherence to these myths.

Many parents believe that a lack of knowledge about sexual issues protects their daughter or son from abuse or the risks involved in sexual experimentation. This is not the case. Young people are much more likely to protect themselves if they have an understanding of just what it is they are protecting. A difficult area for many parents is how explicit they actually need to be when imparting information to their daughter or son. A person with a learning difficulty needs a very clear depiction of what they are being taught before they can understand the concept. A number of years ago I worked with a distraught mother whose 16-year-old daughter had become pregnant. The mother said `I just cannot understand it, I told her “never let a boy touch you on the breasts or on the legs” The tragedy was that her daughter had done exactly as she was told.

There is a common misconception amongst parents that their sons and daughters learn all they
need to know about their bodies, gender differences, puberty, safety, menstrual management and appropriate behaviour at school. This is not the case. The quality of education is only as informed as the teacher educating. Nothing can replace the role that parents need to assume as the primary sex educators of their children. This is even more so in the case of children with disabilities. The most effective education is that which is ongoing throughout childhood and adolescence with frequent revision, reflection and review. One of the most common concerns for parents is at what age and with what information to begin sexuality education. Most parents never actually confront this issue, as their children without learning difficulties will be more easily able to articulate questions as they arise or to seek out information elsewhere.

The belief that sex education needs to be a formal process conducted by an "expert" is wrong. One of the most useful educational methods for people with an intellectual disability is the use of teachable moments. One example of this might be a discussion that you hold after watching a soap opera on TV. It could present an opportunity to talk about relationships and to understand the interpretation the young person has placed upon what they have seen. Another example is to name body parts as you help with their personal care in order to teach an awareness of their body.

Everyone learns about relating to others and behaving appropriately by experimentation and risk taking during adolescence. If this phase is not allowed to occur, the person will not develop the emotional maturity necessary to make healthy choices in terms of relationships and social behavior. Without the opportunity to experience the consequences of their choices, they will be unskilled in future decision making. Young people with an intellectual disability can learn socially acceptable behaviour and how to keep themselves safe. However, in order to build the self esteem and confidence necessary to take control of their behaviour and understand their emotions, education should begin at home from a young age and proceed as a continuum.

A group of courageous mothers, members of the Down Syndrome Association of NSW challenged their own attitudes and values and participated in a sexuality project for themselves and their daughters funded by the Department for Women. The project was funded to work with girls and young women with Down syndrome to enhance their skills for social interaction in the community. Because of the vulnerability of people with an intellectual disability to sexual abuse, it was also hoped to increase the girls' knowledge of protective behaviors. The girls, aged between 11 and 16, lived at home in loving and supportive families. Their mothers' had, understandably, many questions and concerns relating to their daughters' sexuality and the education they should receive, to best prepare them for life.

Nine sessions were held for the girls and four for the mothers on weekends over a year and a core group of mothers and daughters attended all the sessions. Age appropriate groups of eight girls had sessions of up to an hour's duration. "Protective behaviors" was the major theme of their course. Many people believe practicing protective behaviors is a simple concept. In fact it is a very complex set of skills that young people must acquire in order to increase their chances of staying safe. To practice protective behaviors a person must develop skills in assertiveness, self esteem, relationships, self defense, an awareness of feelings and sexual feelings, social behaviors, decision making and body awareness. There was much revising of the information from session to session. A few of the girls had very little verbal communication but their receptive language appeared very developed. This did not preclude them from participating, as most of the education was activity based. One young girl of 13 had very little speech and we were very uncertain as to how much information she was retaining. However one week her mother reported that at camp her daughter had effectively responded to preventing a youth trying to get into bed with her, with the gestures she had learnt in the sessions. It is very important not to believe that someone can't learn because they lack verbal communication. We limit and endanger the whole person by doing so.

As the educational sessions were drawing to a close, it became more obvious to the mothers that they were going to have the ongoing task of continuing the education at home. What we had
achieved was only the basic groundwork. For this reason we developed sessions to train them more comprehensively as the sexuality educators of their daughters. We then ran a session for the mothers and daughters together to transfer the role of educator from trainer to mother. We used an exercise of drawing body parts as a non-threatening way to get mother and daughter working together.

The mothers found the course invaluable as it provided them with the skills and the opportunity to enter into their daughters’ sexuality education. The mothers group sessions were an essential component of the course, as it allowed them to share their fears and concerns in an accepting and understanding environment. The discussions and seminars on specific topics provided insight into possible solutions. The mothers group, through honesty and openness, covered many taboo subjects, which the individual alone would be unable to face.

A number of issues were raised in the families as to how the fathers of the girls were responding to the development of their daughters. They had not had an opportunity to explore their attitudes and values with other parents as their partners had done. To address this we held an afternoon for the men to spend together to explore some of the issues raised by them regarding their daughters’ adolescent development and their responses to it. Many raised fears and concerns about exploitation and pregnancy, but all acknowledged the need for their daughters to have clear, accurate and appropriate information regarding their sexuality.

The project will be followed up by a future opportunity to meet together and to review what information has been retained by the girls, and to obtain feedback from parents as to changes in awareness, questions or behaviours observed by the families. Also, a resource is being developed from the grant, which will offer parents in metropolitan and rural areas access to information on sex education for their daughters. It will also offer information directly to young women with Down syndrome. This will be available in the new year. We thank these parents for having had the courage to explore this area openly and with commitment and to respond to the question "who is the most appropriate teacher in terms of sexuality for my daughter?"

Editor’s note:

Talk to Me is reviewed in this issue on page 203.
CHOOSING A PERSONAL COMPUTER FOR HOME EDUCATIONAL USE

Neil Sleight
Top Class Computers, Oxford, UK

Summary — This article presents an introduction to computers and guidance about selecting a computer for home educational use. The author (a father of a child with Down syndrome) examines the common types of computers available and offers suggestions based on personal experience.

Keywords — Down syndrome, computers

Introduction

For the last six years I have been providing a specialist service to help parents of children with a disability to choose a computer that might be of some benefit to their children. My son James, aged 11 has Down syndrome and so I have a particular interest in helping other children and adults with Down syndrome access computer technology.

If you do not already have a computer and are thinking of buying one, which should you choose and how can they help? With all the special offers available the choice can be positively bewildering. There are three popular choices:

Acorn

The replacement for the BBC. Acorns have been popular in schools, particularly at primary level, and they are liked because they are easy to use, efficient, reliable and virtually impossible to corrupt! However, many schools are now being tempted to switch to PC's simply because they are so widespread. The major drawback to an Acorn, is that they are relatively expensive when you buy them, and do not usually come with much 'free' software, but they do on the whole, last much longer than a PC. The range of special needs software is good, but sadly, Acorn have shown that they are withdrawing from manufacturing computers and whilst you can still buy them they are going to become more marginalised.

Apple Macintosh

Initially popular in America, they are widely available in the UK and well liked, particularly amongst artists and publishers, but it can be more difficult to get hold of software in some local areas. Education software tends to be American complete with accents and spellings. As with the Acorn, they are liked by many people because they are also very easy to use! The range of special needs software is not that good, but is improving.

The ‘personal computer’ (PC)

The PC has taken over the known universe! Generally whenever someone talks about a PC, they mean an IBM compatible Personal Computer running Windows, and these can be a number of popular and widely available makes such as Time, Tiny, IBM, Compaq, Dell and Gateway. Although they are widely used, many people dislike the PC...
because they are technically out of date as soon as you buy them, they are inefficient, and it is quite possible to 'accidentally' corrupt the Windows 95 or 98 operating system, particularly for an inquisitive child! However, they are by far the most widespread computers, with a vast range of software - some good and some not so good!

One important point to bear in mind when buying from these companies is the quality of support available in the event of problems. Check that it is available when you need it and that it is not a premium rate line costing £1 a minute where in my personal experience you can pay for a 20-30 minute phone call and still not get the problem resolved! In this situation the computer may have to be returned to the manufacturer at your own expense. Although perhaps slightly more expensive, it may be worth considering a small local supplier who will probably offer better support because he will know you personally.

When recommending a computer I usually ask three questions:

1) **What does the child use in school?**

   This could be important if they want to easily take work backwards and forwards, or if for instance, they use one important program that is only available on an Acorn.

2) **Do you, as parents need to use a computer to create newsletters or to run a business from home?**

   If so, are you using a particular piece of software at work that must be available?

3) **Most importantly, are you hoping to develop some skills in your child that requires a particular program that may only be available on one type of computer?**

   This would restrict your choice! You should usually look at the programs that you need and then choose a computer that is able to run them.

Having made the choice of computer, how powerful should it be? The best piece of advice I have ever heard is to buy the biggest that you can afford! This is so that it does not become obsolete too soon. Generally a PC is out of date as soon as you have purchased it. The areas that you need to consider are:

**Random Access Memory (RAM)**

For Windows 98 you need at least 32MB (Megabytes) of memory, though will get better performance from 64MB.

**Hard Disk (HD) Capacity**

A minimum of 3GB (Gigabytes) of disk space should be sufficient for most purposes.

**CD-ROM speed**

A fast CD-ROM (32x speed) is important for multimedia applications.

**Central Processing Unit (CPU)**

The processor is the central component of a computer. It executes instructions and controls all of the computers operations. A minimum of a Pentium II 350MHz should be adequate for most purposes.

**Connectivity**

It is useful to have 2 serial ports (for connecting adaptive devices). Modern computers are shipping with Universal Serial Bus ports (USB). However, for compatibility with older adaptive devices, having ‘old fashioned’ serial ports is important.

As always, these specifications are always changing - so the more powerful computer you buy, the longer it will last.

One other point to bear in mind - if the most up to date, powerful computer is not important to you, it is usually possible to pick up 'bargains' by buying an older computer when a new model is released. Now that Pentium III is available it is possible to find some very good prices on older PC's and these are powerful enough for most people.
How can a computer help?

It is all very well buying an expensive piece of equipment but will it be of any benefit? Research and practical experience has shown that they can, particularly with writing and language work. Initially if a young child is struggling to write, using the keyboard will help him or her to develop literacy skills and then to complete schoolwork - even if their writing is illegible! Language and speech skills can be developed by watching and hearing what the computer is doing and one of the significant benefits is that children gain from repetition - and children can repeat something they enjoy endlessly!

Computers do so well because they motivate children to want to do something. The sound and graphics attract them, and because they are not threatening like a teacher - the computer will wait patiently until an exercise is completed and will then reward you. It is important to remember though that the computer is just another tool to help and should not be used in isolation, but alongside other work.

Adaptive devices

There are many adaptive devices available that might help your children if they are unable to use standard equipment on the computer. Some children with special needs, particularly the younger ones, struggle to use the standard keyboard because they do not understand what they are doing. They may also be unable to use the mouse - but then many adults find this difficult!! Devices that may be considered are concept keyboards (of various types), rollerballs, touchscreens, large keyboards, lowercase and alphabetic keyboards (as opposed to the standard qwerty layout). Most children learn their lower case letters first and computer keyboards tend to be uppercase. A cheap alternative to a lowercase keyboard is to use keyboard stickers.

My own philosophy has always been that children should start to use the standard components as soon as they start using a computer, even if their hands are small and they are unable to use the equipment without help. Most children eventual-
Computer software

Inclusive Writer

Inclusive Technology, UK.

Review by Bob Black

Rarely, but once in a while, there comes a piece of software that is ideally suited to the learning needs of children with Down syndrome, most commonly it is in the area of early learning, cognitive skills or speech and language development. Occasionally something comes along that is well suited to the older learner looking in more depth at the acquisition of literacy skills, numeracy or presenting specific subject skills in a more visual and motivating way.

Inclusive Writer, at first glance is just a word processor. "Who needs another word processor" we all ask, "there are far too many to choose from already". The click of a button changes this programme from standard ‘text’ mode to ‘picture’ mode and the reasons begin to emerge.

Picture mode adds coloured images to each word as it is typed. Each letter, word or sentence can be spoken as required. You can also create a second window on the page to contain information, pictures words or actions, which can then be sent directly to the page of work in progress. Word lists, word lists with pictorial support, pictures which send words to the page as well as symbols and single key words, can be used to support a struggling learner to create a piece of work.

For kids who learn well visually all these features are a great bonus to the standard format of a word processor.

Inclusive Writer is not unique in offering spoken word support to a word processor, there are many talking word processor's which have proved ideal for children struggling with text and vocabulary (Pages Textease, Write away, Pendown etc) and there are other programmes that offer picture supported text ( Writing with Symbols etc.), there are also other programmes that offer second windows and grids (Clicker etc.).

Inclusive Writer is unique in that not only does it combine all of these features into one programme but it also offers other great advantages, like a picture and sound supported spell checker, so that a child can be assisted to learn the MEANING of different words which look and sound very similar. The user can very easily switch between text mode and picture mode and children working primarily with text can have the added advantage of...
viewing the picture for an individual word within a piece of work, again to establish the meaning of unfamiliar or confusing words. The flexibility of this programme offers the best features of a host of other programmes so that it can be configured to meet the individual needs of almost any learner without requiring the teacher to have a degree in computer science.

This is without doubt the most versatile writing programme yet released in the English language and it will undoubtedly assist with the task of differentiating learning materials for a whole range of children looking at literacy development, not least for children with Down syndrome working in mainstream classrooms. Children will find mixture of text sound and pictures much more fun and motivating than a standard text word processor. Teachers and parents looking for one piece of software, to learn to use effectively, with the flexibility to include all the best innovations in literacy development using the computer, need look no further this year.

If I have any reservations at all, they are that this programme is primarily a teaching tool and there are simpler programmes for children to use as an introduction to using a word processor independently, manipulating pictures and text to present a piece of work or create fun material like invitations and stories. This programme doesn’t handle this kind of basic function as well as say, Pages or Textease.

It also assumes that the teacher, assistant or parent is already familiar with the basic functions of a word processor and is looking to offer assistance with literacy development, rather than just learning to use a word processor. This is no outrageous assumption, as there are still many in education who view using the computer as a way of simply learning how to use the computer. Far too many schools are forced to relegate their computers to separate rooms, where they are viewed as a separate entity from the rest of the curriculum, access is limited and too often geared to the more able student, rather than to those who would benefit the most from their use. Inclusive Writer may be a little bit ahead of its time. It may need developing to handle photos and artwork more easily, but for those who are looking for an innovative and flexible approach to teaching literacy via a computer there is nothing as well thought out than this at the time of writing.

Inclusive Writer is available from The Down Syndrome Educational Trust, priced £94.00 (incl. VAT) + P&P (Order ref. COMP/0430).

Video reviews

Down to Earth

Review by Sue Buckley

Down to Earth is a 30 minute video about inclusion in primary education, made in Holland. It is available with English subtitles. The video follows the progress of two children with Down syndrome, Milan aged 6 years and Eveline aged 8 years, in their primary school. The children are seen in their classrooms engaged in ordinary class activities, including reading and number work. During the tape the views of the class teachers, the remedial teacher, the head-teacher and the parents are included.

The Head-teacher points out that a school should not wait for a full consensus on inclusion from all staff, but that it is important to have a positive school policy and develop a whole school approach. He also observes that successful inte-
Teachers must plan their lessons ahead and certainly must plan the work for the child with Down syndrome in advance. Teachers must have good classroom management skills. However, he notes that this has made them more skilled teachers and that the work they have adapted for the children with Down syndrome is benefiting other children in school. The children have also benefited for learning to support one another and to work together.

The teachers describe the learning process for them and the way they have learned about the learning strengths and weaknesses of the pupils with Down syndrome. The video shows examples of the visual materials made to support number activities, for example, and the use of computer programmes. The remedial teacher, who provides some one-to-one teaching for the children, describes how she gives extra teaching and practice on the tasks that they will be learning in the class. She also describes how her knowledge and beliefs about Down syndrome have changed because of her experience of teaching Eveline and Milan.

Readers familiar with the UK approach to mainstreaming may be surprised to learn that the children have no additional assistant support in the classroom. Both class teachers are fully responsible for all aspects of the child's education and inclusion. I have to say that this was one of the most positive messages of the very practical and realistic video for me. In countries where inclusion is being supported with individual learning support assistants, the benefits of that support are great when it is planned and used appropriately and it allows much less able children than Milan and Eveline to be included. However, we do see teachers who leave all the responsibility for the child's education to the assistant and this should not happen. When it does, the child is not a fully included member of the class and child and assistant suffer.

The social benefits of inclusion for friendships and inclusion in community activities out of school are well illustrated and parents discuss their motives for seeking inclusive schooling. They also discuss how the process has worked and emphasise the need for good communication and co-operation between home and school.

I would strongly recommend this video to anyone providing training for teachers and for parents who are not sure about inclusion.

*Down to Earth* is a production of the Erasmus University of Rotterdam in co-operation with WBM Productions BV, Hilversum for the Dutch Down Syndrome Foundation, Wanneperveen. It was financed by The Dutch Ministry of Education, Culture and Science and a number of charitable groups working for children in Holland.

Copies with English subtitles will be available from The Down Syndrome Educational Trust but prices and date of release are not available at the time of going to press. Please telephone +44 (0)23 9282 4261 or e-mail sales@downsnet.org for details.

**Listen to Us**

**Review by Sue Buckley**

This 15 minute video has been produced in Australia by young women with Down syndrome for young women with Down syndrome. It begins with three young women introducing themselves, their lives and their work. In the words of one of the presenters, "We are making this video for women with Down syndrome. There are hun-
Hundreds of women with Down syndrome all over Australia - you are not alone. The video addresses three main themes, friendships and relationships, health and work.

In the first section a number of young women talk about the importance of friendships for them and the diversity of friendships that they have. They make the point that friends with Down syndrome provide them with a sense of 'not being alone', but that they value a variety of friends. They comment on some of the issues they may face, for example Gaby says "When people tease me, I always say put your chin up and walk away from them - have confidence in yourself". The video includes shots of adults with Down syndrome engaged in a variety of activities including attending a wonderful ball in black jackets and ball gowns.

In the next section health is discussed and the need to take exercise and maintain a healthy diet. The presenters recommend going to the gym, walking as much as possible and eating a low fat diet. There are shots of the young women at exercise classes. The last part of the video discusses finding work and recommends that young women look for voluntary work or work experience placements as these can lead on to finding a paid job. A recurring theme is 'do not give up - keep trying and you will succeed'.

The video ends with the some comments for the non-disabled viewers as the presenters say "We want to be like everyone else - let us come into your world". As a final piece of advice to women with Down syndrome they say "Don't think about your disability - think about your ability and life goes on".

Listen to Us has been produced by the Down Syndrome Association of New South Wales, Australia, funded by the New South Wales Department for Women. See at the end of the review of "Talk to Me" (below) for further details.

Manual review

Talk to Me

Review by Sue Buckley

A personal development manual for women and girls with Down syndrome and their parents.

This manual, developed from the New South Wales project described is now available from the Down Syndrome Association of New South Wales.

It is an excellent resource for use throughout the English speaking world and I hope it will be translated. The first section is for parents and covers adolescence, feelings, self-esteem and friends, language, attitudes and values, parents' concerns about sexuality education, masturbation, sexual intercourse, protective behaviours, disclosure of sexual abuse and guidance to resources and further reading.

The second section for women and girls, is a set of work sheets to be used with women with Down syndrome, to support the discussion and learning on feelings, self-esteem, friends and sexuality.

The materials are designed to support parents and educators in discussing these topics, the language
is simple and the text illustrated with clear line drawings. Each section contains activities to help the young person to work through and understand the activities and the topic.

This is a very well thought out pack and should be a valuable aid in families and schools. Where a local Down syndrome support group exists, mothers (and/or fathers) might find that the opportunity to discuss the programme with other parents would be helpful. It could be supportive to be able to discuss how they and their daughters are progressing with the materials. The pack could also be used for small group work with women with Down syndrome.

Talk to Me is published by the Down Syndrome Association of New South Wales, Australia. For further information, contact:

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Women’s Challenge Club

This is the name of a club I joined last year. It is only for women over 16 in Devon. The piece in a local paper said that was "a local group which organises challenging and unusual activities for women".

Since I joined I have been:

**Caving.** This was in caves near Ashburton. I got cold, wet and muddy but I enjoyed it. The other ladies kept on saying "Go on Sarah, you are the smallest, you go first".

**Scuba diving.** This was at an indoor pool in Teignmouth. I liked this so much that I am going on a long course to get a PADI certificate and I am going to do it in Malta on holiday this year.

**4 by 4 driving.** This was at Finlake near Chudleigh. We had to show our driving certificates before we were allowed to go. I couldn’t reach the pedals of the car so I didn’t drive but I was a passenger. It was exciting because we nearly turned over.

**Board sailing.** We did this at Decoy lake in Newton Abbot. I got up and sailed a little way into the bank. I am going to do it again.

**Moorland walk.** We started from Dartmeet. It poured with rain all the time. We were out for six hours in the rain and had a picnic lunch in the rain. We were supposed to do abseiling and a river crossing. Some ladies did the abseiling but I didn’t because it was so wet.

We all did the river crossing. My Dad came to pick me up and he was surprised we were all laughing when we got back soaking wet.

**Canoeing.** This was at a quarry near Tavistock. I got on quite well because I have been canoeing before. We were there from 10 until 4 and had a picnic lunch there. We did all sorts of things, some ladies did the capsizing but I didn’t. The hardest bit was paddling backwards.

Next we are going to do horse riding, rock climbing and abseiling. I have been riding before but I don’t know whether I will like abseiling and rock climbing.

Everyone in the club must think of something for us to do. I can do skiing, water skiing and skating so I am going to do one of those. I have met some nice people in the club. They all know I have Down syndrome but they don’t care and I don’t care. They sometimes tease me because I am small but I quite like that because it makes us laugh. I think there should be clubs like this everywhere.

*Sarah Duffen 22.6.99.*
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 successes and solutions, and accounts of difficulties or problems, are encouraged. Shorter or more general accounts of personal experiences may be submitted as correspondence.

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

News

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

Correspondence

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

Editorial review

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

Submissions

Papers submitted to the Journal should be sent to: The Editor, Down Syndrome News and Update, The Sarah Duffen Centre, Belmont Street, Southsea, Hampshire, England, PO5 1NA or e-mailed to dsrp-submissions@downsnet.org

Manuscript Requirements

Please send four copies of your manuscript, which should be typewritten and double-spaced on A4 paper, with any tables or illustrations. At the same time, please submit your article on a 3-inch floppy disk or ‘Zip’ disk in PC or Mac format. Most word processors’ file formats can be supported, though Microsoft Word files are preferred. If in doubt, Rich Text Format (RTF) or plain text (ASCII or Unicode) files are the most compatible. Tables and graphs may be submitted in most major spreadsheet packages’ file formats (Microsoft Excel preferred). Diagrams should be submitted as ‘vector graphics’ file formats (e.g. EPS, WMF, etc.)

Manuscript layout

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

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

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

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

Terminology and spelling: As this is an international and an inter-disciplinary periodical 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 full list of bibliographical references, cited in the text, should appear at the end of the paper. The list should be numbered and ordered by 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):**