Do children and adults with Down syndrome have a specific developmental profile of strengths, weaknesses and needs on which early intervention, education and healthcare should be based if they are to be effective?

Do children and adults with Down syndrome have a specific developmental profile of strengths, weaknesses and needs on which early intervention, education and healthcare should be based if they are to be effective? This was the question addressed at a conference at the end of February, 2005 in Mallorca, Spain. Two hundred and sixty delegates and speakers from 17 countries attended a very worthwhile meeting to address the question of specificity in Down syndrome. The conference was organised by Asnimo (the pioneering organisation for the support of children and adults with Down syndrome established on Mallorca 28 years ago), the University of the Balearic Islands and EDSA (European Down Syndrome Association) with the support of DSI (Down Syndrome International).

The conference opened with a presentation by Juan Perera, of the University of the Balearic Islands and the founder of Asnimo, who stressed the importance of the focus of the meeting – specificity in Down syndrome. The study of specificity addresses the questions:–

- In what precise ways does Down syndrome influence the development of children and adults with Down syndrome?
- Is their profile of development different in some ways from that of typically developing children?
- Is their profile of development different from that of children with developmental delays that have other causes (not Down syndrome)?
- Should education and interventions be adapted to take account of this profile (rather than being the same as those offered to other children with learning difficulties)?

In his presentation, Juan stressed the importance of knowing the answers to these questions in order to effectively address the healthcare, early intervention, educational and social needs of individuals with Down syndrome. The keynote speakers all addressed the issue of specificity in their presentations.

I have summarised the presentations under three headings - as they relate to:-
- biological functioning – physical and genetic effects
- psychological functioning – learning and developing and
- the social or interpersonal issues – specifically the needs of families.

**Biological specificity**

Several speakers addressed research into the physical development of individuals with Down syndrome, at the genetic, pathological, neuropsychological and healthcare levels.

**Pathology**

Krystyna Wisniewski, of the Institute for Basic Research in Developmental Disabilities, New York, USA, described what is known about brain structures at the cellular and structural level, and the new approaches available to laboratories that may give more information about the biochemistry and function of the brain.
The research into the effects of Down syndrome on the way the brain and body functions being conducted by geneticists, biochemists, pathologists and their many colleagues in associated professions is rapidly adding to our understanding and may eventually lead to some therapeutic approaches. However, while there are many differences observed and documented in brain structure and cellular function when the extra chromosome is present, it is not possible at present to draw precise conclusions about the links between these differences and development.

Problems with interpretation

Interpretation of the differences reported is difficult as the structure and functions of the brain develop rapidly from birth to adult life – they are not fixed by genes at birth in any simple way. For example, as any child learns to walk and talk the areas of the brain associated with these activities show very rapid change and development. Input, activity and learning influence brain development, therefore differences in the structure and function of the brain in a child or an adult with Down syndrome may reflect the lack of development of particular skills as well as reflecting the effect of the extra chromosome.

The future

New non-invasive brain imaging methods such as functional MRI (magnetic resonance imaging) and MEG (Magnetoencephalography) which allow scientists to study the brain in action may allow these issues to be explored more effectively as changes in brain function may be able to be studied over time in the same individuals. Some MEG studies of brain function in individuals with Down syndrome are, in fact starting at the Down Syndrome Research Foundation in Vancouver, Canada, and one of their research collaborators, Daniel Weeks of Simon Fraser University, described some preliminary results in an afternoon session at the conference.

Healthcare

The final presentation on the physical effects of Down syndrome was presented by Alberto Rasore-Quartino, from Genoa, Italy. He described the health and medical issues associated with Down syndrome – highlighting those that occur with a greater incidence in children and adults with Down syndrome, and some that occur less often. Almost all medical and health conditions are treated in the same way for a person with Down syndrome but knowing about the greater risks of some illnesses helps parents and physicians to be spot them quickly or to screen for them. Many countries now have this information available as published guidelines, which are regularly updated – see resources at the end of the article. [1]
test. Explicit memory can be further subdivided into Working Memory – the short term memory system used to hold information coming into the brain while processing and understanding it, and used for mental reasoning tasks, and Episodic Memory – the system which stores memories of life events.

Darlynne went on to summarise what is known about the memory strengths and weaknesses usually experienced by individuals with Down syndrome. More is known about the Working Memory system in individuals with Down syndrome than the other types of memory and we know that within this system, visual short-term memory is a strength and verbal short-term memory is a weakness. This will mean that learning to talk and processing spoken information is more difficult for children with Down syndrome.

Longer term, Implicit Memory seems to be a relative strength, though initial learning and consolidation of skills may take longer.

In Episodic Memory, individuals with Down syndrome seem to have some weaknesses in spatial memory, though the ability of many to find their way around their schools and neighbourhoods suggest that not all aspects of spatial memory are equally affected. Memory for autobiographical events may be a weakness as Darlynne demonstrated that individuals with Down syndrome may recall less detail and have more difficulty retelling the details when remembering an event such as a visit.

Implications

She ended her presentation with some pointers for interventions to improve memory skills such as emphasising phonological (speech sound) awareness from infancy, using multi-sensory input for teaching to use visual memory strengths to support verbal memory weakness and building in much practice and repetition.

The specific difficulties in working memory have been researched in some detail and readers can find many papers and practical intervention advice such as Darlynne recommended on the Trust’s information website[2] and in publications[3] – see resource list at the end of the article.

Speech and language

Jean Rondal, of the University of Liège in Belgium, presented a detailed description of the speech and language development of children and adults with Down syndrome. He pointed out that most have strengths in developing vocabulary and in being able to communicate their meaning as they get older, but weaknesses in developing grammar and intelligible speech. He explained the way in which this pattern was different from that seen in individuals with learning disabilities from other genetic causes.

Implications

He also identified the implications of this profile for interventions – which should focus in particular on the need to develop articulation and phonology for clear speech and on developing the use of grammar. However, it is also important to remember when we discuss relative strengths and weaknesses that early vocabulary is learned more slowly than it should be and that all aspects of learning to talk will benefit from targeted games and activities. Jean recently edited a book on speech and language intervention for individuals with Down syndrome which contains research reviews, information and advice on intervention for all aspects, though aimed at professionals rather than parents.[4]

Comparison of cognition, language and social progress

Robert Hodapp, of Vanderbilt University, Tennessee, explored the findings more broadly on intellectual functioning, language and social development.

A specific profile

He drew attention to a specific profile of strengths and weaknesses at this level. He highlighted the frequently reported fact that expressive language usually lags behind non-verbal mental abilities in children and teenagers with Down syndrome, that visual memory is a strength relative to verbal memory and that sociability is usually a strength. This general profile was returned to by two later keynote presenters (Donna Spiker and Deborah Fidler).

Robert and some other presenters considered the ways in which the profiles of children with other genetic conditions such as Williams, Prader Willi and Fragile-X syndromes are similar to the profile associated with Down syndrome. This is of research interest but is not discussed in detail here as it is not directly relevant to understanding how to educate and support children with Down syndrome.

‘Fragile’ development

Robert drew attention to the fact that the developmental progress of children with Down syndrome might be thought of as ‘fragile’ as they seem to need more practice to consolidate their learning and sometimes seem to ‘lose’ skills that they seemed to have learned. While the majority of children with Down syndrome make steady, if slow progress, the rate at which they are learning slows over time and falls behind that of other typically developing children. This is why studies show IQ scores often drop over time as they are based on comparisons with the rate of learning of other children. Children with Down syndrome learn and progress but not fast enough to maintain the same IQ scores from infancy onwards.

Learning styles

Some clues to why this happens may emerge from research identifying learning styles, which could slow cognitive development. For example, studies by Jennifer Wishart at Edinburgh University[5] suggest that toddlers with Down syndrome may ‘misuse’ their social skills to distract parents and teachers when they are faced with learning tasks that they find difficult. They do not then complete the tasks and learn how to solve them, they play social games instead.

Early evidence

This important theme was taken up and explored further by Deborah Fidler of Colorado State University. She reported that her own research shows that this characteristic pro-
file, with social development going ahead of language and cognitive development, can be seen in tod-

ders as well as older children and she argued that it might be possible to
develop intervention strategies to
stop this pattern and to prevent cog-
nitive development falling behind.

Deborah showed clips of videotape
which clearly illustrated toddlers
with Down syndrome avoiding tasks
such as finding shapes in a puzzle
box by playing social games in a way
that other mental-age matched tod-
dlers just did not do.

Implications

Deborah suggested that research
indicates that early problem solv-
ing or ‘strategic thinking’ seen when
infants look for a hidden toy or pull
a string to reach a toy is delayed for
infants with Down syndrome – lead-
ting to the task avoidance social games that they
often develop. She has
just begun to see if train-
ing studies which focus on teaching the toddlers
(at 25 to 35 months) to
solve the cognitive tasks
will accelerate their progress and prevent
the counterproductive
social games from devel-
op ing. This is exciting
work, and references to
Deborah’s studies are at
the end of this article.[1]

Deborah began her research career
with Robert Hodapp and they are
both coming to the UK to take part
in the conference on Early Educa-
 tion and School Education which
is being held in Portsmouth in Sep-
tember this year – see details on
page 101.

Early intervention

Donna Spiker, from the Early
Childhood Programs Centre for
Education in California,[12]continued
to draw on the research into specific
developmental strengths and weak-
nesses to outline an evidence-based
approach to early intervention for
infants and preschoolers with Down
syndrome. Donna is well known for
her work in early intervention begin-
ning with work with children with
Down syndrome more than 30 years
ago in Minnesota, USA with another
pioneer who did much to raise expec-
tations and improve education, John
Rynders.

Clear goals

Donna identified that the goals of
early intervention need to be clearly
defined and broad – specifically to:
• lay the foundations for life-long
   learning and optimise children’s
   progress
• to enable children to participate
   fully in family, school and com-
   munity life
• to promote quality of life for
   families

Evidence based

She stressed the need to base
actual early intervention activities
and programmes on the research
into the profile of strengths and
needs of children with Down syn-
drome but equally to remember the
variability of the children. While
most children with Down syndrome
show the typical patterns, the degree
to which they show them and the
rate at which individual children
progress varies widely.

Donna reminded us that children
with Down syndrome vary widely in:
• rate of development
• levels of achievements
• health status
• behaviour and temperament
and that families are also all
different.

The message is – start with a
knowledge of the research and the
expected profile and then adapt the
recommended approaches to the
needs of the particular individual
and the expectations and preferences
of his or her family.

Five domains

Donna proposed that we plan our
early intervention programmes with
the intention of preparing children
for school readiness and consider
the following framework of five
domains:
• health and physical (including
  motor) development
• cognition and general knowl-
  edge
• communication development
• emotional well-being and social
  competence
• approaches to learning

Under each of these headings, she
highlighted particular issues that
may need to be considered for chil-
ren with Down syndrome.

Health

For example, under health, she
stressed the importance of recogn-
ising that serious heart conditions
or early significant health problems
may affect the babies’ energy to
explore and slow their developmen-
tal progress (though they may well
catch up later) and may increase
parental anxiety. She also reminded
the audience of the need to address
the effects of ‘glue ear’ on learning
language and stressed the need for
more research into the effects of
sleep disturbance on development.

Visual strengths

When considering strategies to
promote cognitive development,
Donna reminded delegates of the
profile of strengths in visual memory
and weaknesses in verbal memory,
therefore the need to use visual
cues for teaching whenever possi-
ble including signing and gestures,
picture, photos, print and the com-
puter.

Play and cognition

She also mentioned the research
already described which shows that
children with Down syndrome may
be less persistent in mastering new
tasks and exploring their toys – and
the need to build in practice to con-
solidate learning. Parents and carers
need to think of imaginative and fun
ways to show children how to solve
tasks and develop games to encour-
age practice.

Parents and children

Donna drew attention to the way
in which all interactions between
parents and infants are influenced
by how the infant behaves – and a
number of studies indicate that par-
ents of babies with Down syndrome
do adapt to their children – often dis-
covering that they have to be a little
more active in stimulating responses
and directing their attention and
learning. We do not know enough
about the way some of these patterns
develop and whether they all help or
hinder children’s progress over time
but we do need to think about this
and do further research.

When considering strategies to
develop communication and spoken
language, Donna identified some
recent studies which indicate the need to enable parents to develop sensitive and effective communication strategies throughout their daily communication with their children and to build speech and language activities into child-centred toy play and motor games. She also emphasised the benefits of using signs and gestures, and the importance of following the child’s lead whenever possible.

Temperaments and behaviour

Under her final heading, she reminded delegates of the importance of adapting to children’s individual temperaments but also the need to encourage behaviour control and socially acceptable behaviour, pointing out that difficult behaviour will interfere with learning and progress and increase parental stress. She then went on to explore briefly the role of early intervention programmes in providing support for parents and families, not just focusing on the child’s progress.

Family adaptation

The needs of families was the topic for another keynote presented by Laura Nota and Salvatore Soresi of the University of Padua in Italy. They reviewed the research into the effects of raising a child with Down syndrome on the family, highlighting findings that indicate that these families experience less stress than those raising children with autism or with other types of learning disabilities and that most cope well.

Why less stress?

There may be a number of reasons for this, including early diagnosis, the availability of early support from services and from parent groups, the sociable nature of children with Down syndrome and fewer behaviour problems. These findings do not suggest that parenting a child with Down syndrome is not demanding or with other types of learning disabilities and that most cope well.

Parent training

It was also suggested that a parent training programme could be helpful in the early years to give parents the knowledge, skills and strategies to face the challenges of raising a child with Down syndrome and promoting their development, the need to negotiate with professionals for services and the need to take care of themselves and their family relationships. The presenters have developed such a programme for parents in Italy.

In conclusion

This summary does not do justice to the quality and detail of the presentations, but hopefully it does give the reader and idea of the key points. There was general agreement that children with Down syndrome do show a specific developmental profile – strengths in social understanding and as visual learners and more difficulties with motor progress, speech and language, and verbal short-term memory. This can be summed having strengths as visual learners and more difficulty in learning from listening. A number of other messages – learning styles, using social strengths to avoid learning, needing more practice to really consolidate learning – also came through.

Is it important that we know this and adapt our early interventions and educational approaches to take account of this profile? Some observers of early intervention programmes were putting this view forward many years ago – suggesting that we would not see benefits for our children if we did not adapt teaching approaches. Each year we learn more in detail about these issues but I would argue that we do have evidence of the benefits of education which takes account of this profile. One example would be the data that we have collected at The Down Syndrome Educational Trust on the outcomes for teenagers in schools in 1999/2000. The teenagers who show significant gains were educated in mainstream classrooms – their education was informed by our knowledge of verbal memory difficulties and being visual learners. Reading played a big part in their teaching programmes – adapted to support their speech and language learning. This study can be found in full at http://www.down-syndrome.info/library/periodicals/dsnu/04/03/.

The presenters identified that the needs of families are different at different stages of children’s lives and that services should recognise this. They identified that breaking the news at the time of diagnosis is still often not done well – either insensitively or in an ill-informed manner. Too many physicians still have outdated knowledge and negative attitudes. They also stressed that each stage brings its own challenges, starting school, reaching adolescence, leaving school and in too many countries real social inclusion and friendships, opportunities for employment, meaningful day-time activity and the chance to live independently of the family are still not available for most adults with Down syndrome. Parent support needs at each stage were identified.
However, I still think that we have a long way to go in ensuring that all those working in healthcare, in early intervention and in our schools are aware of how much we know about the specific needs of children and adults with Down syndrome. Early intervention programmes and nursery staff still need access to good materials and training to ensure they do understand the needs of our children. Mainstream and special education teachers also need access to training and information – in our experience in the UK, mainstream teachers are often better informed than special school teachers. Special school teachers often see children with Down syndrome as like the other slower learners that they work with and this is often not the case.

The exciting messages from the conference for me were that we are becoming better informed in more detail about the early effects of this profile. The work that Deborah Fidler is doing with toddlers is potentially very important. She is looking at the stage at which we begin to see cognitive skills dropping behind social skills by the second year of life and evaluating practical ways of working with toddlers to compensate by teaching them to learn to solve cognitive tasks – and teaching those around them to not be drawn into social games during these sessions. We will watch this work closely.

Resources

1. Healthcare guidelines
Healthcare Guidelines for People with Down Syndrome. EDSA essentials (see p. 106).