Evidence for the benefits of inclusion in education and the keys to success

- In 1987 we conducted a survey with 90 families of teenagers in Hampshire – almost the total group of those living at home.
- The aim was to find out what life was like for teenagers with Down syndrome and their families – all aspects, language, academic progress, practical skills, leisure activities, health, behaviour, family needs. Published as a book but a depressing read – reflects lack of education and opportunities rather than having Down syndrome.
- In 1999 we decided to repeat the survey to see if next generation were benefiting from changes in social attitudes and educational expectations.

Main findings of the study

- No progress from 1988-2000 for special class outcomes – this was a surprise, we expected progress.
- Significant and specific educational benefits for inclusion.
- Teenagers fully included in mainstream classes – gains of more than 2 years in spoken language skills and 3 years in reading and writing.
- Gains in maths, general knowledge and in social independence.
- No differences in personal independence or social contacts out of school.
- Tend to have better behaviour.
Language and literacy - inclusion study

• Very significant gains in literacy (mean gain 3.3yrs) and expressive language (mean gain 2.5 yrs) in mainstream education
• Children fully included in mainstream classrooms
• Access the same curriculum with individual targets and in-class support
• Both groups had same range of abilities and social backgrounds at start of school

Difficult behaviours – inclusion study

• Behaviour better in mainstream settings
• 10% with significant levels of behaviour difficulties in mainstream versus 30% in special schools

Closing the speech-language/non-verbal ability gap

• The mainstreamed children are in a much richer spoken language world
• The mainstreamed children receive more literacy instruction
• The mainstreamed children have a much higher involvement in supported literacy as they are in all lessons

Closing the language/MA gap – changing the ‘profile’

• The last slide demonstrates that it is possible to improve the speech, language and literacy skills of children with Down syndrome and bring them in line with their other skills.
• The immersion in mainstream classrooms and the resulting immersion in reading activities may explain this gain – even for non-readers
• These results support the view that speech and language is held back by hearing and auditory processing difficulties – print makes the language visual
• Importantly it shows we can change the expected Down syndrome profile and reminds us development is dynamic – not fixed at birth

What has produced these gains?

1. Adapting the way we teach to the children’s specific speech, language and cognitive profile, allowing them to access the curriculum and to learn, with support
2. Full inclusion in the mainstream world from infancy – preschool and school
   • Learning with and from age-appropriate peers
   • The other children are role models for language, play and learning – classroom language and social expectations are age-appropriate
• BOTH ARE KEY TO THE POSITIVE OUTCOMES
• All other inclusion studies agree that inclusion done well gives an educational advantage (see references)

Typical profile associated with Down syndrome (see, Hodapp, Fidler, Buckley in DSRP 9 (3) on website)
Our experience of inclusion

- In Portsmouth we began including children in their local mainstream schools in 1988 – with full support of the LA and parents. We still provide the inclusion support service to children and young people in local schools.
- 2 main drivers in 1988 – still the same
- Psychological: development is social, all children are profoundly influenced by learning opportunities and learning from other children – cognitive, language, academic and social learning
- Social: Identity is socially acquired – Who am I? How do others see me? Where do I belong? Changing attitudes, stopping the rejection and exclusion of our children

How are children included?

- Full inclusion in the local mainstream school
- Full inclusion in an age appropriate class
- In class support from teaching assistant (TA) – 15 to 30 hours per week according to need
- Accessing the same curriculum – differentiated for each learner
- Adapted teaching methods to the profile – visual learner, language delayed, sensory impairments, motor needs
- Move up each year with class

Inclusion support in Portsmouth

- Provided by ‘specialists’
- At least one monitoring visit each term
- Support for access to curriculum, social development and behaviour, and for focused interventions
- Training for staff – teachers and assistants, parents, publications, information
- Regular liaison with parents and school team – equal access to service by parents and professionals
- A similar model is used in other successful Local Authorities

What have we learned since 1988?

- We have learned by working with schools locally and across the UK - provide a lot of training
- ATTITUDES are THE KEY TO SUCCESS – that is believing in inclusion and ‘seeing child first’, not the disability
- Commitment from the top, Head and Governors
- Planning at whole school, class and individual levels
- Good communication – a team approach
- Willingness to learn and to problem solve

Attitudes and rights

- We learned very early how very different schools and teachers can be
- We also learned about the need to address attitudes and beliefs about Down syndrome
- We had some of our most able students rejected even though their work was within the range in the class
- We had some of our most disabled students welcomed and fully included
- This is still happening despite disability discrimination law
- It is a professional duty for a teacher to meet a child's needs – with necessary support and training - not an option

Head and Governor’s responsibilities

- Recognition that the evidence shows that inclusive schools are the best for all pupils and in an inclusive ethos academic results go up
- Inclusive ethos = respect for individuals, support for individual strengths, build self-esteem, self-respect and respect for others, build mutually supportive and caring environments in which everyone flourishes – pupils and staff
- “Everyone has had a good day and wants to come back tomorrow” – One Head’s definition of a successful school
Joyce, junior school head teacher

Key points

- 'It has been a huge professional development for me – to understand these children can cope well in mainstream school
- That must be the same for all the staff who have worked with the children and will impact on all their teaching
- For recognising individual needs and how to deal with these
- Very positive'

Bronwen and Joe (year 4, 8-9 years)

Whole school ethos = training

- Inclusion training for all – will lead to whole school change – this should be mandatory
- Attitudes – all staff need to believe in inclusion
- Disability awareness training for all
- Information on specific disabilities
- Whole school responsibility
- Special educational needs co-ordinator (SENCo) or inclusion manager should be part of senior management team – this shows school's priorities and commitment to SEN

Karen, junior school Special Educational Needs Co-ordinator (SENCo) (ages 7-11) - from Downsed Primary Inclusion DVD

Key points

- At first teachers made comments that these were not the sort of children they expected to be teaching
- It has changed their outlook
- We get pleasure from them – a sense of achievement
- When one of the children, who is not very sociable, speaks with staff, we think 'we did that here'.
- It is good for the staff and puts development into perspective
- Sometimes we expect big leaps from children, the small steps are just as good.'
Flexibility needed

- No – ‘we always/only do it this way!’
- A range of teaching methods – team teaching, small groups, peer tutoring, working with teaching assistants
- Flexible and planned use of resources – people, space, materials, information
- Training – for staff at all levels
- Time management – for planning, meetings
- Remembering this is for ALL children

Parent involvement

- Partnership with parents based on mutual respect is essential to success and to maximising learning and social opportunities
- Parents are usually experts on their child’s disability or needs and have played a major part in early education programmes as teacher if they have Down syndrome.
- They can continue to support teaching aims and help their child consolidate and generalise learning out of school

Supported by key recommendations from Fox, Farrell, Davis

Four key factors schools need to look at (2 year study, 18 English schools)

- The centrality of the class teacher in the management of the inclusion of the child
- A complementary rather than compensatory relationship between the support assistant and class teacher
- The capacity of the class curriculum to include and involve the pupil with Down syndrome
- The quality of communication between the teacher and pupil, teacher and teaching assistant, teacher and advisory teacher, teacher and parents/carers

Differentiation, age 8

Class project about water. Key questions and answers; a word web. Vocabulary and sentences explain:
- rain, cloud, river, lake, pond, reservoir, people and water use, transport, contaminated water
Access the curriculum in the classroom!
E.g. numeracy lesson, adding coin values

Challenges for parents

- Too many families find that getting their child included is still a battle – despite their child’s right to a place in a mainstream school within their community
- Some face negative attitudes in schools
- Some face negative attitudes in Education Authorities
- Many feel that it is a constant struggle – each year they find themselves needing to advocate for their child, they see poor teaching practice and unwillingness to learn about their child’s needs, to value their child
- Many are on the end of the ‘bad news book’ only hearing the negatives

The good news – it can benefit everyone

- While we hear about the bad news and bad practice, many families, children and schools have a great time
- Children with Down syndrome of all levels of ability and need flourish and make good academic progress, they have real friends in school and community
- Teachers tell us how much all the children in the class have benefited and how well they understand and support the child with Down syndrome
- Teachers tell us how much they have learned and how much their teaching skills for all children have benefited

Recent research

- See the work of Gert de Graaf in the Netherlands – he has reviewed the literature and conducted his own in depth research
- Review chapter at <http://www.downsyndroom.nl/reviewinclusive>

Key points

- ‘Our experience has been phenomenal in terms of our level of understanding of learning – what learning is about
- We’ve had to rethink our preconceptions about what it is to be academic
- and what people need to have to achieve
- It has broadened our whole awareness of education’
De Graaf et al. findings – benefits of inclusion

- Children in regular education had better academic outcomes in reading, writing and maths with the strongest effect for reading.
- Even after accounting for the effects of IQ, age, non-academic skills and parental education – which did effect outcomes.
- Parental time spent on academics at home also mattered.
- One factor is that more teaching time given to academics especially reading in regular school placements.

De Graaf et al. findings – benefits of inclusion

- Papers presented by Gert and his team at World Down Syndrome Congress, South Africa 2012.
- Additional analyses – more years in regular education the greater the benefit for reading controlling for T1 reading scores and over an above IQ (N=115, 2006-2010).
- Children with IQs above 50 with mainly special school history were compared with children with IQs 35-50 included in regular school. (410 children in study in 4 IQ groups). The children with lower IQs but in regular classrooms were ahead on reading, writing, math, self-help, language and computer skills.

Why these findings?

- The social world – typical language, typical social behaviour, typical learning models all around.
- Higher expectations.
- Better quality teaching as well as more teaching time given to academics.
- More individual planning – small steps and intensity matter – see our RLI data.
- Classroom support – often one-to-one. This enables student to stay on task and complete work successfully.
- Access to a wider curriculum.
- Support of peer group.

References – DSE UK Inclusion studies

- Articles 1-3 are available in full on http://www.down-syndrome.org/

The evidence for a specific phenotype or profile

- See Deborah J. Fidler (Colorado State University) and colleagues for a recent reviews of the evidence.
- The Emerging Down Syndrome Behavioural Phenotype in Early Childhood. Infants and Young Children (2003) 18, 2, 86-103
- And free access articles - preschool, primary and teenage profile papers.
- Down Syndrome Research and Practice 9 (3) special section on the specific profile free at http://www.down-syndrome.org/research-practice/.
Individual differences in response to reading intervention for children with Down syndrome

Sue Buckley
Kelly Burgoyne, Fiona Duff, Paula Clarke, Maggie Snowling & Charles Hulme

THE UNIVERSITY OF YORK

Background: Reading in Down syndrome

- Reading can be a strength
- More information and resources are needed to support educators
- Evidence suggests comprehensive reading instruction works for many children with Down syndrome
  - Goetz et al. (2008): 8 vs. 7 children; 40min daily for 8 weeks
  - Lemons & Fuchs (2010): 24 children; 30min daily for 6 weeks
- But, this approach does not improve the reading skills of all children, with or without Down syndrome (Goetz et al., 2008; Hatcher et al., 2006; Lemons & Fuchs, 2010)
- A combined intervention approach may be particularly effective for these children (Buckley et al., 1996; Burgoyne, 2010)

From research to practice

- How do teachers and parents make use of research studies?
- What do they need to know?
- Does group data tell us anything about individuals?
- If an RCT has demonstrated effectiveness of an intervention, does that mean all individuals in the population studied will benefit?
- Do these questions challenge the way we present and publish data?

The study - project Aims

- Funded by £481,000 BLF grant:
  - To evaluate the impact of a reading and language intervention programme on the literacy skills of young children with Down syndrome
  - To equip educators with resources and skills to help develop children’s early literacy skills


Background: Supporting reading in typical development

- Effective reading interventions
  - Combine training in (Hatcher et al., 2004, 2006)
    - letter knowledge
    - awareness of speech sounds (phonological awareness)
    - links between letters and sounds
  - book reading
- Spoken language skills influence response
  - For children with poor spoken language, interventions that combine training in reading and language may be more effective (Duff et al., 2008)

Background: Adapting teaching for children with Down syndrome

- Slower progress
  - Small steps, intensive daily instruction, frequent opportunities for revision and consolidation
- Short term memory: visual stronger than verbal
  - Visual supports for learning
- Difficulties with comprehension
  - Emphasise and support reading for meaning from the outset
- Behaviour and attention
  - Short, varied activities and teaching approaches that ensure success
- Difficulties with phonological awareness and phonics
  - Explicit instruction and frequent practise, alongside sight word instruction
- Delayed language
  - Combine reading with language instruction
- Wide range of ability
  - Scope to tailor programme for individual abilities
Randomised Control Trial

Programme Structure

- Daily 40-minute individual sessions, delivered by trained teaching assistants
  - Teaching sessions (1 to 4, 6 to 9): routine structure
  - Consolidation sessions (5 and 10): reflect and revise
- Two interactive components
  - Reading Strand
  - Language Strand
- Prescribed programme
  - Set out in manual
  - Opportunities to tailor sessions to play to individual's strengths and address weaknesses

Session Structure

- Reading Strand (20 mins)
  - Reading easy level book 2-3 mins
  - Reading new instructional level book 5 mins
  - Sight word learning 2-3 mins
  - Letters, sounds, phonology 5 mins
  - Introduce new instructional level book 5 mins
- Language Strand (20 mins)
  - Vocabulary: Introduce new words 5 mins
  - Vocabulary: Reinforce meaning of new words 5 mins
  - Expressive language: Use new words in connected speech 5 mins
  - Expressive language: Use new words in written language 5 mins

Participants

<table>
<thead>
<tr>
<th>Pre-test</th>
<th>Autumn 09: 6:10 (5:02 – 10:00)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Average Raw Score</td>
</tr>
<tr>
<td>Expressive vocabulary (max. 170)</td>
<td>28.70 (12.78)</td>
</tr>
<tr>
<td>Receptive vocabulary (max. 170)</td>
<td>35.43 (13.53)</td>
</tr>
<tr>
<td>Early word reading (max. 79)</td>
<td>6.54 (11.30)</td>
</tr>
<tr>
<td>Letter-sound knowledge (max. 32)</td>
<td>14.28 (8.69)</td>
</tr>
</tbody>
</table>

Effect of Intervention: Week 20
Our findings

1. On most measures intervention group progressed faster - shown as green bars above the line
2. Some small gains, some larger – 4 reached statistical significance = letter knowledge, word reading, phoneme blending, expressive vocabulary
   These reflect directly taught skills - and these gains did not yet transfer to gains in spelling, non word reading or standardised language measures. Maybe not a surprise given the demands of the reading tasks and the extent of language difficulties for children with Down syndrome
3. The waiting control group progressed faster when they moved to the intervention – and showed similar gains to the intervention group

Reading Progress – individual differences

- Wide variation in reading progress
  - range raw score gains 0-36
- 21 children unable to score at t1; 5 at t3
- 10 children age-appropriate reading at t3
- Predictors of progress in reading (F(3,48)=11.22, p<.001)

<table>
<thead>
<tr>
<th>Predictor</th>
<th>B</th>
<th>S.E.</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>0.62</td>
<td>4.82</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Receptive Language</td>
<td>0.51</td>
<td>3.97</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Sessions attended</td>
<td>0.30</td>
<td>2.69</td>
<td>.001</td>
</tr>
</tbody>
</table>

Individual differences in progress

- Wide variation in progress made on intervention – some children made rapid progress, other slower progress and some very little progress
- What influenced progress? - age, receptive language and no. of sessions
  - Younger children tended to make more progress – those starting at 5 and 6 years (1206.51 gain 3.06 62.77 months at t1 pooled SD 6.05 11.40 all)
  - Children with better receptive language tended to make more progress
  - BUT not all 5 and 6 year olds went fast and some older children did, some children with more delayed receptive language progressed with reading
  - Children receiving at least 80% of the intervention sessions made more progress
  - Other (unmeasured) factors may also contribute

Reading progress in relation to age at start

Reading progress in relation to language ability
**From research to practice**

- How do teachers and parents make use of research studies?
- Does the data suggest it will help my child? If he is 8 years with limited language?
- Teachers need to know what works for which children in what circumstances.
- Do these questions challenge the way we present and publish data? Is case data as important and we should do both?
- Does a programme that works when supported by expert team work without that support?
- Follow up survey in progress – early results promising
- 90% think child is benefitting, 81% plan to continue more than a year.

---

**Feedback from teaching assistants**

- Teaching staff delivering intervention reported that:
  - Though the intervention was hard work they enjoyed it
  - Increased confidence and feelings of competence
  - Improved skills and expertise
  - Increased self-esteem and greater job satisfaction
  - Potential for application to other children in the classroom

I am absolutely adamant that this programme (even though it is tailored for and suits children with Down syndrome extremely well) can be successfully used on many more children that struggle with a regular reading scheme.

---

**Teaching assistant and parent feedback**

- Supported evidence from standardised tests

I think this is the intervention has made the biggest difference to X out of everything we have done over the last 2.5 years.

His vocabulary has extended and his use of words in the correct tense has improved too.

Many people have commented on how much X’s speech has improved and that they can now understand him.

---

**The RLI handbook**

- Instructions for how to deliver each component, ideas for teaching activities and adaptations to suit individual abilities
- Practical information on delivering intervention, record keeping and collaboration
- Resources for assessments and teaching, planning and record keeping
- Video illustrating each component and activities for teaching, including examples of children with different starting levels, strengths and weaknesses
- Background information on development and evaluation

http://www.dseinternational.org/en gb/resources/teachingrli/ for more information on the intervention.
Evidence-based practice: what does research tell us about the specific language and learning needs of children with Down syndrome

Setting the scene for effective education

- What do we know about the effects of Down syndrome on development?
- First – the big picture across all areas of development
- Second – a closer look at the areas of specific weakness
- Do we know any of the reasons for this profile?
- What are the implications of what we do know for intervention strategies?
- If we apply these strategies – can we improve the areas of weakness and change the profile?
- Applies in special and mainstream classrooms – and to many other children

Down Syndrome Education International

- The charity exists to advance the education and development of individuals with Down syndrome worldwide through research, information and training.
- Since 1980, we have had an active programme of research and provided services to children, families and schools.
- This has enabled our team to work directly with children in early intervention and in classrooms, as well as collect research data.

Keep in touch with our work

- We have a large information site at Down Syndrome Online at http://www.down-syndrome.org/
- This has much information for teachers in the Down Syndrome Issues and Information Education series (DSII)
- There is also a wealth of papers by world leading experts in the Down Syndrome Research and Practice section
- Teaching materials, books and videos can be found at our online store at http://store.dseusa.org/

Down Syndrome Education International

- This mix of focused research interests and direct involvement in education has given us a unique opportunity to set up interventions and then follow children in longitudinal studies, as well as ask more experimental research questions.
- We give high priority to sharing information directly with parents and practitioners through publishing, website and training activities.
- For more information on the work of the charity see http://www.dseinternational.org/ and note linked US site http://www.dseusa.org/en-us/
Effects of Down syndrome on development

- Most children will have delayed development
- There is a very wide range of individual differences from mild delays to more severe levels of disability
- For most children, severity of disability cannot be predicted at birth or in early years
- Not all aspects of development are equally delayed
- Research in the past 15 years has highlighted a profile of strengths and weaknesses
- We can use this information to be more effective in helping children reach their full potential – development is not fixed at birth

Weaknesses

- Motor Skills
- Social understanding, empathy & social skills
- Speech and Language
- Hearing and Vision
- Visual short-term memory
- Verbal short-term memory
- Self help and daily living skills
- Information processing
- Learning from listening difficult
- Non-Verbal Mental Age
- Number
- Reading
- Strengths

The specific developmental profile associated with Down syndrome

- Good social interactive skills
- Good empathy and positive personalities
- Sensitive to failure and negative emotional cues
- May use social skills to distract/avoid difficult tasks
- Good behaviour relative to mental ability and communication skills
- Good practical self-help/daily living skills over time
- Delayed early motor development – affects early learning through play and handwriting progress

Cognitive strengths and weaknesses

- Specific verbal short-term and working memory difficulties
- Strengths in visual short-term memory and processing
- Academic learning
- Strengths in reading – can be at age level (10%+)
- Number more difficult – often 2 years or more behind reading

The importance of the weaker areas – speech, language and working memory

- Language underpins cognitive and social development for all children
- Words for knowledge – vocabulary size
- Language for remembering, thinking, reasoning
- Language for self-control and planning
- Language for dealing with emotions and worries
- Language for communicating with others
- Language for friendships
- Any child with language delay will have cognitive (mental) delays (including executive function difficulties)
- Working memory deficits will affect all learning

Learning to talk

- Talking is for communicating – getting the message across, engaging with others
- Starts with looking, smiling, pointing – non-verbal skills for commenting, requesting, answering
- Then words – vocabulary learning – working out meanings and saying the words
- Then sentences – grammar learning – stringing words together for more complex meanings
- Talking requires clear speech skills – takes time for all children
Speech and language development

For most children with Down syndrome spoken language is delayed for mental age but they show an uneven profile

- Communication skills are usually good
- Vocabulary is delayed but grows steadily
  - understanding is ahead of expression
- Grammar is a challenge and lags behind vocabulary
  - tend to be ‘telegraphic’ talkers, using key content words
  - understanding is ahead of expression
- Clear speech is a challenge and speech is often difficult to understand

Vocabulary/grammar link

- Vocabulary size ‘pushes’ along grammar development in TD children (Bates et al.)
- Children with Down syndrome have a vocabulary delay
- 200-250 words are needed before grammar starts
  - Understanding will be ahead of production
  - 200-250 words understood to begin to understand grammar
  - 200-250 spoken words to begin to use grammar

There will be many children with Down syndrome in kindergarten and elementary schools who do not yet have 250 words in spontaneous spoken language

Vocabulary/grammar link (Pennanen, Buckley & Archer 2000)

Penmanen et al study

- MacArthur Communicative Development Inventory (CDI)
- Parent completed expressive language measure for early language. 210 children in the study
- Only 84 children had a score on the grammar scale of the CDI
- These 84 children had an average productive vocabulary of 416 words
- The ‘no grammar’ group an average productive vocabulary of 154 words
- Same pattern as TD children but ‘too late’?

Locke’s views – and others

- TD 18-36 months Down syndrome at same point at 3-8 years
- John Locke has argued that there is a ‘sensitive’ period for language development in the brain
- The analytic and computational ‘centres’ for grammar – rule driven language activated by vocabulary growth
- If not activated then these areas will be used for other purposes
- Developing control over phonology also vocabulary driven? Also a computational system to be turned on by input and activity?

Practical implications

- Need to develop vocabulary as fast as possible
- This data led us to develop DSE Vocabulary checklists (3 checklists covering 800 word early vocabulary)
- Enables a record for each child of words understood and spoken
- Enables teaching targets to be selected
- All this refers to spoken words so speech production difficulties also need to be addressed
- Need to hear and discriminate and produce all speech sounds of language – from first year of life
Practical implications

- Speech discrimination and sound production at 6-8 months predict language development i.e. spoken words in TD children
- DSE has developed materials for both speech and language work under See and Learn title.
  - http://www.seeandlearn.org/en-gb/about/
- In apps and in printed kits
- See and Learn Number and Memory in development

Why this learning profile?

- Hearing loss plays a part
- Auditory processing may play a part
- Slow vocabulary learning may delay grammar
- Difficulties with verbal short-term memory play a part
- We know nothing of early speech discrimination in children with Down syndrome
- Speech difficulties will delay language development
- We know very little about causes of speech-motor issues
  - Not just a motor issue
  - Planning component
  - Verbal short-term memory component

Looking in more detail at weaker areas – working memory

- Working memory is the immediate memory system that supports all mental activity
- The working memory system has several components
  - The central executive which holds and processes information
  - Supported by limited capacity stores
    - the visual spatial scratchpad - to hold visual information
    - the phonological loop - to hold verbal information
    - both hold information from senses for about 2 seconds
  - the episodic buffer which links to long-term memory
  - Capacity in working memory increases with age

Baddeley’s 2006 Working Memory Model

Central Executive

Verbal short-term memory
Phonological loop

Episodic buffer

Visual short term memory
Visual-spatial scratchpad
Working memory is important for all children

- 'Working memory is the mental workplace in which information can be temporarily stored and manipulated during complex everyday activities.'
- listening to another speaker
- decoding an unfamiliar word whilst holding the meaning of the previously decoded text in mind
- writing while formulating the next part of the text
- engaging in mental arithmetic
- Predicts academic progress better than IQ (Alloway)

Verbal short term memory & language

- The phonological component supports verbal short-term memory (VSTM)
- Verbal short term memory span improves with age and can be measured with digit and word span tasks
- Verbal memory span is influenced by increases in speech perception and production rates, and by reading ability
- The phonological loop influences the learning of vocabulary and syntax – and the storage and processing of sentences
- It seems to influence spoken language output – may play a role in holding the phonological structure of speech prior to output (Gathercole et al 2005)

Working memory in children with Down syndrome

- 4 year old typically developing children have a digit span of 3, 16 year olds a span of about 6/7, teenagers with Down syndrome only have spans of 2/4
- For children with Down syndrome their verbal working memory skills are delayed for mental age – a specific deficit
- Most of the research has measured verbal and visual short term memory
- Visual short-term memory skills are significantly better than verbal short-term memory skills in most studies
- However, recent Italian research has indicated visual STM impaired if material require simultaneous rather than sequential processing (dual tasks) and also central executive impairments (Lanfranchi et al.)

Why this profile?

- A number of research studies by Chris Jarrold and team at Bristol University, UK have shown that the deficits cannot be explained by hearing loss or speech difficulties
- They suggest a phonological loop deficit – which will affect word learning as well as memory.
- They have shown children with Down syndrome have specific difficulty learning the accurate phonological or sound pattern of words
- There is some evidence that training can improve working memory function including computer training – Cogmed (Bennett, Holmes, Buckley 2013)
- Early speech perception and production difficulties could be causal as system has to tune to native language

Executive functions now being studied

- Important role of language in executive functions
Implications for intervention and education

Use social/emotional strengths

- Build on emotional responsiveness – encourage social communication, looking, smiling, gesture
- Early social communication underpins cognitive and language development
- Talk to and play naturally with children
- Build on social understanding – encourage ‘good’ behaviour

Always encourage AGE appropriate behaviour – do not ‘baby’ or ‘spoil’ child (or adult), have clear expectations and boundaries

• Target speech and language difficulties from infancy and through school years
• Remember that children are visual learners
• Use reading to teach talking from early (2 to 3 years) and through school years
• Learning from listening will be specially difficult but learning from looking easier so always use visual supports – signs, pictures, reading, the computer
• Enable understanding to be demonstrated without the need to say it – choosing, pointing, selecting

Compensate for ‘weaknesses’

- Hearing, vision – regular checks, good health care – speak clearly, use signs, limit background noise. Involve sensory impairment team
- Address working memory difficulties with sound and word discrimination games from infancy, improving spoken language development and playing memory games
- Encourage motor development at all times
  - Active practice
  - Encourage active movement through play
  - Sporting skills are good for fitness as well as social skills

In summary

- Children with Down syndrome are visual learners
- They find learning from listening particularly difficult
- This effects learning to talk and it effects processing spoken language and instruction

If we plan interventions to

- To focus on teaching spoken language
- Support all learning visually – especially with print
- To improve and compensate for working memory

Can we make a difference?

Our data for teenagers taught in this way from preschool years suggests we can

Closing the speech-language/non-verbal ability gap

- This is another version of the earlier coloured profile slide
- One group show the expected profile – social and practical strengths, language weakness
- The ‘adapted input’ mainstream group show language skills as good as their other skills – it is possible to change the profile
Language and literacy - inclusion study

We can change the profile

The evidence for a specific phenotype or profile

Relevant research evidence is growing

References – speech, language and memory

References – cognition and education


• The syndrome behavioural phenotype: implications or practice and research in occupational therapy. Occupational Therapy in Health Care (2011) 25, 7-25

And free access articles - preschool, primary and teenage profile papers

• Down Syndrome Research and Practice 9 (3) special section on the specific profile free at

http://www.down-syndrome.org/research-practice/

We can make a difference

• We can make a difference

• Outcome data from a study of teenagers shows significant gains in spoken language as a result of comprehensive interventions from early years

• Significantly better language and clearer speech

• Significantly better reading skills

• Linked to immersion in mainstream school/teaching to the profile of strengths and weaknesses

• Buckley, Bird, Sacks and Archer – see at

http://www.down-syndrome.org/reports/295/


Importance of full inclusion in changing the profile


Improving Memory in Children with Down syndrome

Stephanie Bennett¹, Joni Holmes², Sue Buckley¹,³
¹ University of Portsmouth, UK, ² University of Cambridge, UK, ³ Down Syndrome Education International, UK.


Memory and Down syndrome

Research has shown that individuals with Down syndrome have a specific deficit in the verbal memory domain. Their visual memory skills are often less impaired. (e.g. Chapman & Seung, 2005/Hick, Botting & Conti-Ramsden, 2005).

This graph shows baseline AWMA data from our current study (N=25)

M CA 8.6 (range 7-12)
M MA 5.4 (range 4-8)

Memory training and Down syndrome

Rehearsal training:

Rehearsal training studies have found that some improvements were made, but were only modest gains and were not sustained – and indeed gains did not transfer to working memory (Broadley et al. 1994, Comblain, 1994, Laws et al. 1995, Connors, 2008).

There is a clear need to further explore memory training programmes and see 1. if they lead to lasting memory gains 2. lead to other cognitive or language gains

Cogmed Published Research

1. Adaptive training that taxed working memory to its limits was associated with substantial and sustained gains in working memory, with age appropriate levels achieved by the majority of children compared with non adaptive training (Children with low WM). (Holmes, Gathercole & Dunning 2009)

2. When compared with Medication, Cogmed training showed greater benefits on all aspects of working memory (Children with ADHD). (Holmes & Gathercole 2009)

Cogmed Published Research 2

1. Working Memory training can improve cognitive functioning in pre-school children, with transfer effects of visuo-spatial training to the verbal domain of WM (Typical Pre-School Children) Thorell et al, 2008).

2. Cogmed has also been shown to help adults who have had a stroke & other adults with memory difficulties. (Westerberg, 2007).
Working Memory and the Brain

Training induces significant increases in WM-related activity in the prefrontal cortex. Westerberg (2007)

Training results in changes in the density of cortical dopamine D1 receptors. McNab & Varrone Feb 2009.

Cogmed JM/RM – See www.cogmed.com

- JM = 75 games
- RM = 200 games
- Designed by psychologists and computer games designers
- Adaptive training on a trial by trial basis constantly adapting to each individual’s WM capacity

Pilot

- 5 Children with Down syndrome
- Trisomy 21. Mainstream Schooling
- Cogmed training completed at home
- 1. PPVT (Peabody Picture Vocabulary Test)
- 2. 8 Subtests of the AWMA (Verbal & Visual STM/WM)
- 3. BRIEF parent version

Main Study

- 24 Children with Down syndrome
- Trisomy 21. Mainstream, 3 SEN. 7-12 years
- Cogmed training completed at school
- RCT random assignment (G1 N=12, G2 N=12)
- 1. KBIT 2 (Kaufman Brief Intelligence Test)
- 2. 4 Subtests of the AWMA (Verbal and Visual STM/WM)
- 3. BRIEF P parent version (preschooler)

21 children completed training (Group 1 = 10, Group 2 = 11)

Measuring Memory (AWMA, 2007).

- Verbal STM – e.g. Forwards digit span
  - 7
  - 6
  - 5
  - 4
- Visual STM – e.g. Block recall
- Visual WM – e.g. Odd one out

Baseline Scores – Kaufman AWMA

<table>
<thead>
<tr>
<th></th>
<th>CA</th>
<th>MA V</th>
<th>MA NV</th>
<th>Verbal STM</th>
<th>Verbal WM</th>
<th>Visual STM</th>
<th>Visual WM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 1</td>
<td>113.60</td>
<td>63.80</td>
<td>68.90</td>
<td>13.10</td>
<td>7.50</td>
<td>11.60</td>
<td>6.90</td>
</tr>
<tr>
<td>Group 2</td>
<td>113.64</td>
<td>65.64</td>
<td>66.00</td>
<td>13.09</td>
<td>8.82</td>
<td>13.64</td>
<td>8.73</td>
</tr>
</tbody>
</table>

Cogmed Memory Scores (post training)

<table>
<thead>
<tr>
<th></th>
<th>STM</th>
<th>WM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Task*</td>
<td>P</td>
<td>H</td>
</tr>
<tr>
<td>Start</td>
<td>3.51</td>
<td>3.37</td>
</tr>
<tr>
<td>Highest</td>
<td>4.51</td>
<td>4.59</td>
</tr>
</tbody>
</table>

* Pool, Hotel, Rollercoaster, Twister, Wheel Of Animals, Ferris Wheel, Bumper Cars
Raw AWMA Scores (pre and post training)

<table>
<thead>
<tr>
<th>Group</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>13.10</td>
<td>8.40</td>
<td>15.10</td>
</tr>
<tr>
<td>2</td>
<td>13.40</td>
<td>8.80</td>
<td>15.30</td>
</tr>
<tr>
<td>3</td>
<td>13.09</td>
<td>8.82</td>
<td>15.45</td>
</tr>
</tbody>
</table>

Group 1:
- Time: 13.10, 13.40, 13.09
- STM (Short-Term Memory): 7.50, 8.40, 8.82
- WM (Working Memory): 11.60, 8.40, 13.64

Group 2:
- Time: 13.40, 12.91, 13.09
- STM (Short-Term Memory): 8.80, 7.45, 8.82
- WM (Working Memory): 11.20, 12.27, 13.64

BRIEF-P – Executive Functioning Measure

Measures EF in 5 key areas.
- Working Memory – Hold information in mind for purpose of completing/sticking with an activity.
- Shift – Move freely from one situation to another, solve problems flexibly.
- Inhibition – Controls impulses and behaviour at correct time/context.
- Emotional Control – Modulates emotional responses appropriately to situation.
- Plan/Organise – Anticipates future events/consequences.

High scores indicate difficulties in that area – average score for typical child is 50.

Executive Functioning

<table>
<thead>
<tr>
<th>Group</th>
<th>Time</th>
<th>Inhibition</th>
<th>Shift</th>
<th>Emotional Control</th>
<th>Working Memory</th>
<th>Plan/Organise</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1</td>
<td>71.10</td>
<td>70.50</td>
<td>61.30</td>
<td>80.10</td>
<td>68.80</td>
</tr>
<tr>
<td>2</td>
<td>2</td>
<td>65.20</td>
<td>60.60</td>
<td>57.80</td>
<td>71.70</td>
<td>61.09</td>
</tr>
<tr>
<td>1</td>
<td>1</td>
<td>67.73</td>
<td>61.18</td>
<td>61.27</td>
<td>76.36</td>
<td>65.00</td>
</tr>
<tr>
<td>2</td>
<td>2</td>
<td>62.90</td>
<td>56.63</td>
<td>57.09</td>
<td>72.18*</td>
<td>62.09</td>
</tr>
</tbody>
</table>

BRIEF-P – Standardised Score Change

Factors associated with greater gains
- Time of day – children did better in morning
- Children with higher verbal IQ
- Intensity – no of sessions completed
- Children in mainstream school settings compared to self-contained or special classrooms
- Engagement of teaching assistants
- Fewer behavioural issues

Individual differences need more attention in all studies

Summary

- Cogmed training was feasible and improved short term visual memory for children with Down syndrome in our study.
- Cogmed training may be suitable for younger children with appropriate support – also depending on their existing memory skills.
- Children who completed Cogmed training had less problems on WM & SHIFT (BRIEF-P).
- Gains are sustained – children likely need more frequent practice. JM intervention programme less intensive than RM (75 activities v 200) – current case study of RM showing continuing gains.
Future directions – memory improvement

- Larger trials of Cogmed or similar with longer term follow up to see if there are gains in language, academics, behaviour, attention...
- Roche work http://www.dseinternational.org/en-gb/news/2013/03/14/roche-advisory-board/
  - Compound selective for brain receptors that contain the GABA-A α5 receptor subunit

Evaluating therapies

- Substantial challenges involved in developing assessments that are reliable and sensitive enough to demonstrate treatment effects
- Substantial challenges in getting young people with Down syndrome to ‘do their best’ in assessments
- Quality at sites – strict adherence to protocol and attention to detail
- Placebo effects???? Due to attention or knowing you are in trial and expected outcomes?
- Outcome measures must relate to real world quality of life improvements but these may need more than drug – opportunities for new learning

The problem of ‘placebo’ effects

- These have been large in other trials involving individuals with Down syndrome and may have obscured efficacy of drug
- Many adults lead boring and impoverished lives – taking part in a trial gives them attention
- Carers may also improve their opportunities and experiences once they are in a trial

Patient Reported Outcomes - challenges

- Measures available for parent/carer reported are not ideal
- We should be developing tools to allow individuals with intellectual disabilities and language difficulties to report
- Too often they have no chance to contribute from their own perspective
- What is their daily experience like, their thoughts and feelings?
- How do they understand and communicate about health issues? Or mental states?

Evaluating therapies

- Learning outcomes are influenced by the type, intensity and the quality of the therapies and education provided
- Pharmaceutical trials will need to take these issues into account
- Pharmaceutical therapies may be less effective than developmental interventions or more effective when combined (perhaps more so during specific periods of development)
- They may not work for everyone – variability
- Need large sample sizes - costs

The international Down syndrome community

- Crucial role for community in providing clear and balanced information about this research to families and people with Down syndrome
- Support recruitment
- Responsibility to provide accurate information, and to be cautious about the eventual benefits that this research may bring
- Need a real team effort with researchers, clinicians, people with Down syndrome and their families working together
Acknowledgements

- Sincere thanks to all the children, their teaching assistants, their parents and the schools.
- The study was funded by The Daily Thomas Charitable Fund £45,000 and Down Syndrome Education International £10,000

References

Update on dual diagnosis issues – Down syndrome and autism spectrum disorders

Sue Buckley

What are autistic spectrum disorders?

Three core features co-occurring

• Impairments in communication (CI) – delayed language (*no gesture/sign use)
• Impairments in social interaction (SI) – do not understand and relate socially and emotionally to others
• Repetitive and restrictive behaviours and interests (RRBI) – do not develop imaginative play, cling to routines, do not like change, may ‘over-react’ to sensory stimuli

See p 116 Sue B review for ICD 10 criteria

What is known about ASDs?

• ASD occurs in 1% of the general population and in up to 40% of people with intellectual disability
• There are many more males – around 4 males to 1 female
• Its causes are not known - have a strong genetic component(s) – probably many disorders
• Diagnosis is based on clinical judgement
• The 3 separate 'symptom' clusters common in general population – may have different genetic underpinnings (Skuse 2007)

Studies of prevalence – ASD and DS

• Over past 25 years, some dozen papers have reported cases of children and adults with Down syndrome and autism. Also surveys in the UK and Sweden which suggest that about 5-7% of children with Down syndrome have ASDs. The size of the groups studied has varied widely as have the measures used.
• Recently some more rigorously studies have been carried out – Colorado team, DiGuiseppi, Hepburn, Fidler
• 123 children, aged 2 to 11 years, Modified Checklist for Autism in Toddlers (M-CHAT) younger children - Social Communication Questionnaire for older children

Study of prevalence – DiGuiseppi et al.

• Give a weighted prevalence of 18.2% for children with ASD and within that group 6.4% were diagnosed as autistic.
• If assume they identified all the children with ASD in the total population then prevalence is 7.4% they conclude that this may be the more accurate prevalence figure and is identical to that found in a UK population based study.
• If the 11 children with ASD and mental ages at or below 18 months removed the estimated weighted prevalence of ASD was 13% and none had a diagnosis of Autism. And ASD prevalence was 9.3% for children with mild cognitive impairment, 19.9% for those with moderate cognitive impairment and 13.1% for those with severe cognitive impairment.

Screening tools – 50% false positives

• Specificity: The screening tools did find 88% of the children later diagnosed with ASD – they were screen positive (12% were missed and rated as screen negative).
• Sensitivity: The screening tools produced about 50% false positives – that is children who looked to be ‘at risk’ and have ASD but who turned out not to have the condition. A false positive screen result was significantly more likely if the child had a hearing problem or a persistent vision problem. Children born prematurely were nearly four times more likely to have a false positive screen. There was no association between a history of heart disease, ear infections or seizures and false positive screen.
Confounding with severe cognitive impairment

- Autism was diagnosis in 28% of the children with severe cognitive impairment and in no children with mild or moderate impairment. PDD-NOS (ASD) was diagnosed twice as often in children with moderate or severe impairments than in those with mild cognitive impairment.
- Experienced clinicians and they report that they were confident that those diagnosed with autism did have ‘true’ autism co-occurring with Down syndrome. They report that they were less confident about the rest of the children diagnosed as ASD (PDD-NOS in USA).

Is it autism?

- They suggest that ‘children with inflexible behavioral styles or difficulty coordinating multiple behaviors may screen positive for autism and that further evaluation by an experienced clinician is necessary to disentangle executive dysfunction from poor social relatedness.
- They recommend that ‘clinicians should supplement screening questionnaires with direct observation, attending to social orienting, communicative intention, emotion contagion and other aspects of core social relatedness that differentiate autism from global developmental delay’, p 189.

Longitudinal study – Colorado, Hepburn 2007

- 20 young children with Down syndrome (2 to 3 years old) - comprehensive evaluation by experienced clinicians using the ADOS-G and ADI-R. 18 were reassessed two years later (at 4 to 5 years). Their findings support the conclusions of the study just described.
- At T1 two child were diagnosed as autistic. A third child was considered for a diagnosis of ASD based on her ADOS-G scores - felt the diagnosis was not correct as she engaged in smiling and reciprocal social interaction.
- 9 children met partial criteria for an ASD diagnosis but were not diagnosed with either autism or ASD.

Item analysis – Colorado group in press

- Compare 3 groups DS only, DS autism and DS PDD
- Pointing, play and social referencing identified autism and ASD groups as different from DS only
- Showing, imitating, attracting attention, understanding separated autism from ASD and DS only
- Impairments in stereotyped behaviours/repetitive interests more pronounced in DS autism group but seen in 85.2% of all the children with Down syndrome. More repetitive hand movements in DS only than DS autism group!
- Sensory issues – no group differences
- DS autism = lowest cognition & authors ask is it autism?
Aims of DSEI longitudinal study

- Track changes in the behaviours diagnostic for autism
- Track range of onset of these behaviours and changes with time – to increase our ability to correctly diagnose and support from as early as possible
- 40 children recruited 18 to 42 months in 2008
- Bayley III assessments
- M Chat - parent completed screening tool
- Carey Toddler Temperament Scale
- Detailed sign and spoken language records
- Early Support Developmental Journals for babies and children with Down syndrome

The M Chat – a screening tool

- Designed as an early detection tool
- For TD children 16-30 months
- 23 item questionnaire completed by parents
- Six ‘critical’ questions
- Fail or ‘at risk’ if you fail:-
  - 2 of the 6 critical questions
  - Any 3 items
M Chat also used in Denver Down syndrome population study by DiGuiseppi et al (2010)
Full details and references to M Chat at http://www2.gsu.edu/~psydlr/Diana_L._Robins,_Ph.D.html

M Chat results – over 3 years

- ‘Fail’ on the critical items (2 or more of 6 items failed)
  - 2008: 5
  - 2009: 2
  - 2011: 2
- ‘Fail’ on total fail score (3 or more of 23 items failed)
  - 2008: 7 (10)
  - 2009: 3 (4)
  - 2011: 1 (2)

(n) = number who fail if we leave in walking and deafness

Number of children failing questions by year

<table>
<thead>
<tr>
<th>Social initiation/engagement</th>
<th>2008</th>
<th>2009</th>
<th>2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>Point to request</td>
<td>7 (6)</td>
<td>2 (1)</td>
<td>1 (1)</td>
</tr>
<tr>
<td>*Point to show</td>
<td>6 (5)</td>
<td>3 (2)</td>
<td>2 (2)</td>
</tr>
<tr>
<td>Attract attention to activity</td>
<td>6 (6)</td>
<td>2 (1)</td>
<td>2 (1)</td>
</tr>
<tr>
<td>*Bring objects to show</td>
<td>4 (4)</td>
<td>4 (3)</td>
<td>2 (1)</td>
</tr>
<tr>
<td>*If you point at toy across</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>room does child look</td>
<td>5 (5)</td>
<td>0 (0)</td>
<td>2 (2)</td>
</tr>
<tr>
<td>*Does child imitate you (face)</td>
<td>1 (1)</td>
<td>2 (1)</td>
<td>1 (1)</td>
</tr>
</tbody>
</table>

* indicates the 6 critical items
(N) Indicates no of ‘fail’ children with overall ‘fail’ score

Number of children failing questions by year

<table>
<thead>
<tr>
<th>Other play/behaviours</th>
<th>2008</th>
<th>2009</th>
<th>2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>Make unusual finger mvmts</td>
<td>8 (6)</td>
<td>2 (1)</td>
<td>1 (0)</td>
</tr>
<tr>
<td>Stare/Wander to no purpose</td>
<td>7 (4)</td>
<td>9 (4)</td>
<td>4 (1)</td>
</tr>
<tr>
<td>Does your child pretend</td>
<td>4 (4)</td>
<td>0 (5)</td>
<td>1 (1)</td>
</tr>
<tr>
<td>Not play without fiddling</td>
<td>5 (4)</td>
<td>1 (1)</td>
<td>2 (1)</td>
</tr>
<tr>
<td>Oversensitive to noise</td>
<td>6 (4)</td>
<td>8 (2)</td>
<td>21 (2)</td>
</tr>
<tr>
<td>*Does child respond to name</td>
<td>2 (1)</td>
<td>0 (0)</td>
<td>2 (2)</td>
</tr>
<tr>
<td>*Interest in other children</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

* indicates the 6 critical items
(N) Indicates no of ‘fail’ children with overall ‘fail’ score
Children ‘at risk’ in 2011

Commonly failed social items by these children at some point
- 7. Using index finger to show interest in something - 3
- 9. Bringing objects to show - 2
- 19. Does child attract attention to his/her activity – 3
- 17. Does your child look at things you are looking at – 2
- 6. Point to request – 2
- *15. If you point does your child look – 2

Do not lack core social/emotional relatedness but this looks more like ASD

Further analyses
- Doing an item by item analysis
- To identify age at which most children with Down syndrome have the key pointing and showing behaviours
- Our further analysis of the data on many aspects of these children’s development and health issues may enable us to clarify what is happening developmentally – especially on the cognitive and communication fronts - for these children and we want to see how the behaviours have changed over time
- We have video records of children’s assessments

Implications
- The majority of children ‘at risk’ do not lack core social interactive skills at Time 2 in 2009 (age 2:9-4:6) – they ‘fail’ on other items
- Diagnosing ASD before 5 years of age unreliable
- Even at time 3 in 2011 this is not typical ‘core’ autism and we need to consider what this means for interventions
- Our further analysis of the data on many aspects of these children’s development and health issues may enable us to clarify what is happening developmentally – especially on the cognitive and communication fronts - for these children and we want to see how the behaviours change over time

Autism and Down syndrome
- Confounded with more general brain damage, seizures
- Confounded with multiple and profound disability
- Symptoms are not a typical ASD pattern – social strengths and social engagement usually still evident
- Regression possibly 50% of cases and later (40-46 months) rather than 18-19monthCastillo et al (2008)
- We need to understand the ‘ASD’ profile seen in children with DS in more detail – treatments could be different (Moos and Howlin)
Challenges in ASD diagnosis in Down syndrome

The overlap with levels of intellectual impairment or disability
- Some individuals have not reached the developmental level to show behaviours being assessed as ‘missing’
- Generalised damage to brain or ‘social brain’ (Skuse 2007)
- When ASD symptoms seen in genetic syndromes – each has a syndrome specific pattern of these ‘autistic traits’ – showing similarities and differences and further detail on these are needed (Moss & Howlin 2009)
- No evidence that applying ‘autism’ therapies works or that they are appropriate (Moss & Howlin 2009)

Repetitive behaviours – current work

Leekham et al 2007 Typically developing 2 year olds
- suggested 4 sub-scales: unusual sensory interests, repetitive motor movements, rigidity/adherence to routine and preoccupations with restricted patterns of interest.
- These sub-scales closely resembled repetitive behaviour subtypes within the ICD-10 criteria for autism. Repetitive behaviours of every type were frequently reported.
- repetitive behaviours represent a continuum of functioning that extends to the typically developing child population.

Repetitive behaviours and Down syndrome

Evans and Gray 2000 – no difference between TD and Down syndrome children, mean MA of 5 years on repetitive, compulsive behaviours. (Age 3 to 21 years) most behaviours reduced with increasing mental age.
Glenn & Cunningham 2007 – children with Down syndrome higher levels of routine and compulsive like behaviours at all MAs.
For younger MA and CA children- RCBs positively associated with adaptive behaviours
For children with MAs over 5 years and all adults – associated with behaviour problems

Positive function of repetitive behaviours

Routines universal and likely to have adaptive function
- enhance socialisation and simplify complex situations (e.g. in children’s repeated play patterns and games)
- help to reduce and master anxiety, such as bedtime routines which have familiar sequence of actions
- help to develop a sense of security and control over the environment
- routines increase child’s feelings of competence, reduce anxiety and free up cognitive capacity all of which foster likelihood child will explore and learn new ideas.
- ‘just right’ behaviours – lining up toys, or same plate – understanding order and dev. capacity for classification See Glenn and Cunningham 2007

Executive function suggestions
- Inability to generate novel behaviour may lead to display of a restricted set of behaviours
- Impaired capacity to inhibit behaviour – ‘locked into’ one line of behaviour
Teach appropriate play activities, use activity schedules with picture prompts, behaviour modification

Repetitive behaviours – current work

Turner, M. (1999) useful review of repetitive behaviour in autism – need to understand the different behaviours within this global term.
- Looks at theories
  - reduce arousal,
  - operant behaviour,
  - impaired mentalising,
  - weak central coherence,
  - executive function deficit

Sensory Profiles

See Rogers, Hepburn, Wehner 2003

- 7 subscales – Short sensory profile (Dunn) = tactile, taste/smell, movement, visual/auditory sensitivities, under responsive/seeks sensation, auditory filtering, low energy/weak
- Sensory reactivity of group with developmental disabilities same as MA matched TD children
- Children with autism or fragile X higher scores

Chen et al. 2009 – repetitive behaviours and sensory processing, used Short Sensory Profile in autism. Significant correlations between the two – needs to be explored further.

Conclusions

- ASD and Down syndrome can co-exist but social impairment less – not typical
- Currently over-diagnosed – need refined criteria
- Family history may help – genetics
- Repetitive behaviours, sensory issues not ASD
- Confounded with severe cognitive impairments and brain damage
- Detailed longitudinal studies needed to trace needs and outcomes
- Careful evaluations of interventions needed – no evidence typical autism approaches will work

Interventions at present

Autism intervention literature – see reviews, Howlin, Magiati & Chapman, 2009 and Kasari, Freeman et al 2005
Evidence of effectiveness for
- Behavioural approaches, highly structured teaching
- Teaching joint attention and play skills – see Kasari et al 2010 and Aldred et al 2004
Down syndrome – no studies yet but we would recommend
- teaching communication - requesting, pointing,
- teaching signs and words
- teaching problem solving and play skills
- Play partners – to scaffold play and learning

References – autism and Down syndrome

Review article
Colorado studies

Descriptive studies
References – Down syndrome


References – repetitive behaviours


References – interventions


References and resources

- Current questions in autism research – is it one disorder?

Useful practical book