

Understanding the needs of children with Down syndrome – speech, language and cognitive profiles

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Down Syndrome Education International

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

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 see www.downsed.org

Acknowledgements

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- All have contributed to this work, to my understanding of the issues and to this presentation

Overview

- Effective interventions, education and therapies need to be based on knowledge of a child's specific learning needs
- Effective intervention needs to acknowledge the social nature of development and learning
- Providing therapy and education programmes designed to address specific learning needs and delivered in an inclusive preschool system will be the most effective
- What evidence do we have to support this view?

The evidence for a specific phenotype or profile of strengths/weaknesses

- See Deborah J. Fidler (Colorado State University) for a recent review of the evidence – preschool age
- *The Emerging Down Syndrome Behavioural Phenotype in Early Childhood*. *Infants and Young Children* (2005) 18, 2, 86-103
- See also Freeman, S. F.N. & Hodapp, R.M. (2000) *Educating children with Down syndrome: Service needs and new educational strategies*. *Down Syndrome Quarterly* 5, 1-9. – school age
- Down Syndrome Research and Practice 9 (3) special section on the specific profile online

Effects of Down syndrome on development?

- Not just a pattern of global delay
- a specific profile of learning *strengths* and *difficulties* – *THE PHENOTYPE*
- These specific learning *strengths* and *difficulties* are increasingly well understood
- The children's *difficulties* can be addressed with effective interventions
- The children's *strengths* can be used to support learning

Development is a dynamic process

- Development is NOT fixed at birth
- Brains are affected by input and activity
- Development is a social, interactive process – influenced by the quality of social relationships, social opportunities and learning environments
- Inclusion - in the family, in the community and in the school - is essential for optimal progress
- We can all make a difference
- INCLUSION PLUS FOCUSED INTERVENTIONS

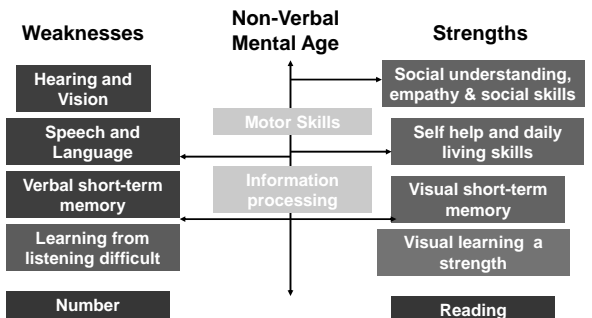
The specific developmental profile associated with Down syndrome – overview 1

- A profile of moderate to severe learning difficulties – a wide range of individual differences
- Good social interactive skills, good empathy and positive personalities
- Good behaviour relative to mental ability and communication skills
- Sensitive to failure and to emotional cues
- Delayed motor development – affects learning
- Good practical self-help/daily living skills over time

The specific developmental profile associated with Down syndrome – overview 2

- Specific speech and language delays
- Speech and language delayed relative to non-verbal mental abilities
- Significant risk of vision and hearing difficulties
- Strengths in use of gesture and motor responses
- Memory strengths and weaknesses
- Significant delay in development of working memory – especially verbal component
- Strengths in visual processing and visual memory

Typical profile associated with Down syndrome (see Robin Chapman, Robert Hodapp, & Deborah Fidler)



Speech and language profile for children with Down syndrome

- Language is delayed but an uneven profile
- Communication skills are usually good
- Vocabulary is delayed but grows steadily - understanding is ahead of expression
- Grammar is more difficult – tend to be telegraphic talkers - understanding is ahead of expression
- Clear speech is more difficult

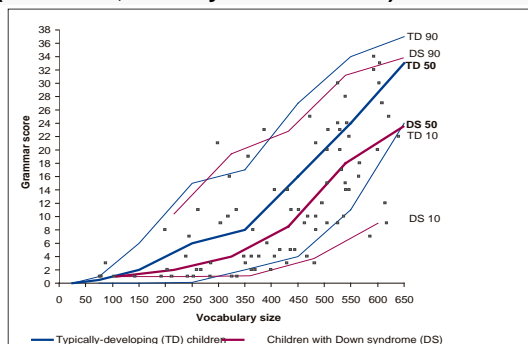
The importance of speech and language for all aspects of development

- 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

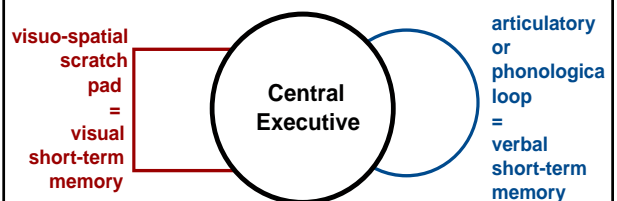
Improving speech and language

- Need to work on all aspects
- Speech clarity
- Vocabulary
- Grammar
- Communication
- Use our checklists plus observation diary for assessment and planning
- Progress with grammar is linked to total vocabulary size – see next slide
- (See Dsii Speech and Language Materials)

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



Working memory



Working Memory Model (Baddeley and Hitch)

Working memory

- Working memory is the immediate memory system that supports all mental activity
- Working memory has two stores one for visual/spatial information and one for spoken information –
- These stores hold information for about 2 seconds
- Short-term verbal memory span improves with age and can be estimated with digit tasks
- (See Dsii Working Memory book)

Working memory - development

- 4 year old 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 visual spans are better than their verbal spans
- In typical development, span is influenced by increases in speech perception and production rates and by reading ability
- Reading ability, speech and language knowledge and memory development are interactive, gains in one produce gains in another

Working memory is important for all children 1

- 'Working memory is the mental workplace in which information can be temporarily stored and manipulated during complex everyday activities such as understanding language and doing mental arithmetic'.
- 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

Working memory is important for all children 2

- 'Any task where the child is required to process new information and to integrate it with stored knowledge – learned or just encountered'.
- Children in reception classes with poor working memory measures for age scored poorly later in the Standard Achievement Tests.
- Gathercole, S., & Pickering, S. (2001) Working memory deficits in children with SEN. *British Journal of Special Education*, 28, 2, 89-97.
- Children's Working Memory Battery. Psychological Corporation.

Implications for education 1

Build on social/emotional strengths

- build on emotional responsiveness – encourage social communication, looking, smiling, gesture
- talk to and play naturally with children
- build on social understanding - encourage 'good' behaviour, starting with settled feeding and sleeping routines
- Always encourage AGE appropriate behaviour – do not 'baby' or 'spoil' child, have clear expectations and boundaries

Implications for education 2

Compensate for 'weaknesses'

- hearing, vision – regular checks, good health care – speak clearly, use signs, limit background noise
- encourage and teach speech sound discrimination
SPEECH SOUND DISCRIMINATION IS IMPORTANT FOR TALKING AND FOR WORKING MEMORY
- (Speech sound discrimination skills develop significantly in the first 12 months of life)
- Provide speech sound practice, word and sentence practice - talking needs to be worked on

Implications for education 3

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

Implications for education 3

- Address working memory difficulties with sound and word discrimination games from infancy, improving spoken language development and playing memory games
- Use visual supports for all learning and visual timetables in preschool
- Encourage age-appropriate social behaviour from early – with other children as good role models
- Ensure warm, supportive relationships and environment

Implications for education 4

- Encourage motor development at all times
- Motor skills require active practice – keep child active – include in all physical education – balance takes longer to develop
- Encourage active movement through play
- Sporting skills are good for fitness and for social opportunities
- Handwriting will come with practice – ensure child is seated in right size furniture, feet on floor
- Teach computer skills – mouse and keyboard

Using signs as a bridge to talking 1

- Signs help to compensate for hearing loss
- Children with Down syndrome are good at gesture
- Being able to sign reduces frustration, as spoken words are delayed relative to comprehension
- Signs support good communication and language teaching
- Signs aid comprehension of new words – speech alone is not sufficient

The benefits of using signs 2

- Signs aid intelligibility when speech not clear
 - Children supported by signing have larger vocabularies when they start school
- BUT REMEMBER**
- Speech sound work should be a priority from infancy, alongside signing
 - The focus should always be on using signing as a bridge to speaking and by school age signs should only be used as necessary for individual children
 - Teaching talking is the priority in school

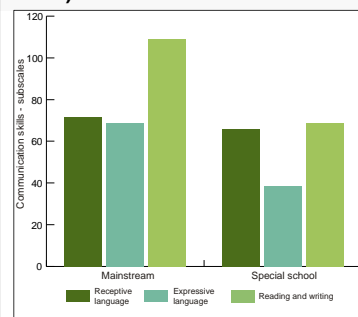
teaching reading to teach talking 1

- Learning from listening is difficult and learning from looking is easier
- Printed words seem easier to remember than spoken words
- Reading activities can teach new vocabulary and new grammar
- Reading supports spoken practice of words and sentences
- 'Teaching reading to teach talking'
- (See DSii series Reading Books for all age groups)

The benefits of teaching reading 2

- Spelling and phonics support the development of articulation and phonology so improve speech intelligibility
- Research studies show that teaching reading *improves speech, language and working memory skills*
- Children do not need to be independent readers to gain these benefits – supported reading will produce at least some of the gains

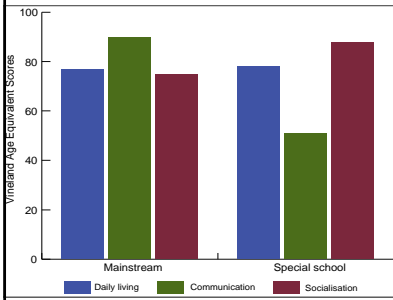
Inclusion study (Buckley, Bird, Sacks, Archer, 2002)



Vineland Adaptive behaviour Scale – age scores

- 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

Closing the speech-language/non-verbal ability gap – inclusion study (Buckley, Bird, Sacks & Archer, 2002)



- 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/non-verbal MA gap – changing the ‘phenotype’

- 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

What has produced these gains?

- 1. Full inclusion in the mainstream world from infancy – preschool and school
- Learning from and with age-appropriate peers
- The children are role models for language, play and learning – classroom language and expectations are age-appropriate
- 2. Adapting the way we teach to the children's specific speech, language and cognitive profile, allowing them to access the curriculum and to learn
- BOTH ARE KEY TO THE POSITIVE OUTCOMES

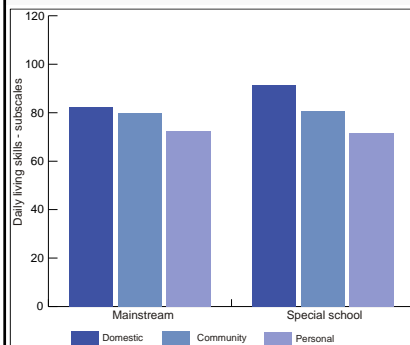
Inclusion study – Portsmouth UK (Buckley, Bird, Sacks & Archer 2002)

- Compared achievements of all teenagers with Down syndrome in 1987 and in 2000 in one county
- In 1987 – all in special education classrooms (SLD)
- In 1999 – about one-third full inclusion from 5 yrs
- Compared special class (SLD & MLD) and full inclusion outcomes with carefully matched groups
- One area of Hampshire county included children from 1988, earlier than the rest of the county and adapted the teaching to address their needs
- No difference in ability or social background at 5

The benefits of inclusion in school

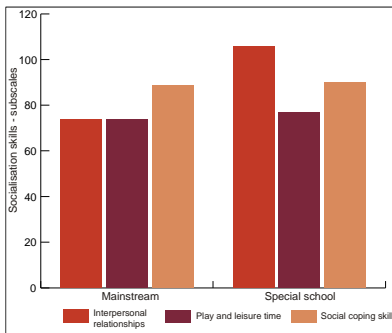
- No progress 1988-2000 for special class outcomes
- Significant educational benefits for inclusion
- Teenagers fully included in mainstream classes
 - gains of more than 2 years in spoken language skills and 3 years in reading and writing
 - gains in maths, general knowledge and in social independence
 - no differences in personal independence or social contacts out of school
 - tend to have better behaviour

Daily living skills – inclusion study



- No significant differences on daily living skills
- Even though special schools may say they make these a priority rather than academics
- Measure is Vineland Adaptive Behaviour Scale

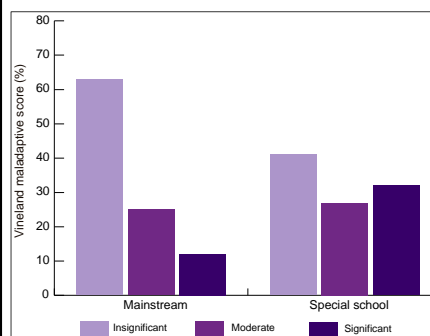
Socialisation skills – inclusion study



- Special school group are 2 years older on average
- Interpersonal relationships, the over 17 age group only produce difference – more special friends, boyfriends, girlfriends reported by special school students

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Difficult behaviours – inclusion study



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

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Education and intervention resources

Down Syndrome Issues and Information series on Development and Education - Range of small books on all aspects of development by age group (0-5, 5-11, 11-16) – an overview, speech and language, motor skills, social development, reading and writing, number and school issues

- Available as a pack or as individual books
 - On-line versions coming soon as funding permits .
- Videos on 1. inclusion in school 2. development 0-18mths 3. speech and language 18mth – 4 yrs.
- see website at www.downsed.org for purchase details.

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Further resources - preschool

- Early Support www.earlysupport.org.uk
- Developmental journal for babies and children with Down syndrome – birth to 5 years
- - a record to celebrate achievement, to share with all professionals and to help to identify areas of need
- Further articles on profile issues by Debbie Fidler and others in Down Syndrome Research and Practice volumes 10 and 11 – shortly to be available online see www.downsed.org

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References – Hampshire Inclusion studies

1. Buckley, S., Bird, G., Sacks, B., & Archer, T. (2002). A comparison of mainstream and special education for teenagers with Down syndrome: Implications for parents and teachers. *Down Syndrome News and Update*, 2(2), 46-54 and 2. in Down Syndrome Research and Practice. 9 (3) pp 54-67 (with full data tables).
3. Buckley, S., Bird, G., Sacks, B., & Archer, T. (2002). The achievements of teenagers with Down syndrome. *Down Syndrome News and Update*, 2(3), 90-96.
4. Buckley, S. J. & Sacks, B. (1987). *The adolescent with Down syndrome: Life for the teenager and for the family*. Portsmouth, England: University of Portsmouth.
- Buckley, S., Bird, G. & Sacks, B. (2006) Evidence that we can change the profile from a study of inclusive education. Down Syndrome Research and Practice. 9 (3) pp. 51-53.
- Articles are available in full on <http://www.down-syndrome.org/>
- All available in print from The Down Syndrome Educational Trust

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Information and advice provided by Down Syndrome Education International builds on 30 years of research examining how to meet the learning needs of people with Down syndrome.



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