Down Syndrome Education Conferences

Speech - Language Track
Ages 7-16

high quality, evidence-based guidance and information for professionals and families

Thank you to our conference sponsors!
When all you see is Down syndrome, you’re not seeing the whole picture!

The Down Syndrome Guild of Greater Kansas City (DSG) is a nonprofit organization whose mission is to provide support and resources to individuals with Down syndrome, their families and the professionals who serve them. DSG seeks to provide the entire community with information and education to broaden awareness and foster positive attitudes regarding people with Down syndrome.

We are so proud to be celebrating our 30th anniversary in 2014. DSG has been a part of some amazing advancements for people with Down syndrome during the last 30 years. Early intervention therapy, inclusive education, community integration and medical advancements mean longer lives and greater opportunities for our friends to achieve their full potential. DSG is so grateful for our partnerships with hospitals, schools, therapy centers, community centers, corporations and funders which allow us to dream big for the next 30 years.

Our 1200 members with Down syndrome invite you to join DSG and help us create a more inclusive world by offering your support in the following ways:

- Volunteer for the DSG
- Host a Dress Down for Down Syndrome Day
- Sponsor an event
- Hire an employee with Down syndrome
- Collect items for our new parent baskets

With your help, we can achieve great things!

For more information: www.kcdsg.org | 913-384-4848 | info@kcdsg.org
This track offers information and practical advice about the speech and language learning development and needs of children and young people with Down syndrome. This unique opportunity will provide you evidence based information, advice and guidance drawing on the latest scientific research that will assist you in working with your clients who have Down syndrome.

## Speech-Language Pathologist Track

### Friday, January 24th

<table>
<thead>
<tr>
<th>Time</th>
<th>Early Years Track (0-6 Years)</th>
<th>Childhood Track (7-16 Years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:30 AM - 8:00 AM</td>
<td>Registration</td>
<td>Continental Breakfast (included with registration fee)</td>
</tr>
<tr>
<td>8:00 AM - 9:00 AM</td>
<td>Keynote –What does research tell us about the speech and language profile of individuals with Down syndrome and the design of effective therapies?</td>
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<tr>
<td>9:15 AM - 10:00 AM</td>
<td>Developing early language—vocabulary and grammar</td>
<td>Developing and supporting working memory</td>
</tr>
<tr>
<td>10:15 AM - 11:15 AM</td>
<td>Teaching reading early-benefits for later reading and language</td>
<td>Developing language—vocabulary and grammar</td>
</tr>
<tr>
<td>11:30 AM - 12:30 PM</td>
<td>Developing and supporting working memory</td>
<td>Activities to improve speech clarity</td>
</tr>
<tr>
<td>12:30 PM - 1:30 PM</td>
<td>Lunch On-site (included with registration fee)</td>
<td></td>
</tr>
<tr>
<td>1:30 PM - 2:30 PM</td>
<td>Developing communication skills and supporting children with ASD profiles</td>
<td>Teaching reading and using reading to support speech language development</td>
</tr>
<tr>
<td>2:45 PM - 3:45 PM</td>
<td>Activities to improve clarity of speech</td>
<td>Developing communication skills and supporting children with ASD profiles</td>
</tr>
<tr>
<td>4:00 PM - 4:30 PM</td>
<td></td>
<td>Closing remarks and Q&amp;A</td>
</tr>
</tbody>
</table>

### ASHA Continuing Education Units

This program is offered for .7 ASHA CEU (intermediate level; professional area).
Becky Baxter CertMRC SLT

Becky is a speech and language therapist registered with the Royal College of Speech and Language Therapists and the Health Professions Council in the UK. She runs her own practice ‘Let’s Go’ providing a range of speech, language and education services – see http://www.letsgouk.org/.

Becky has had experience of working with children across a broad range of difficulties in a number of different settings including mainstream pre-schools and schools, a Specific Language Impairment Unit in a mainstream school and Great Ormond Street Hospital where her role included the management of caseloads, the use of a variety of assessments and intervention techniques and writing reports for external professionals including annual reviews.

She worked at Down Syndrome Education International full-time for 4 years where her roles included delivering specialist early development groups for children with Down syndrome from birth to school age; managing an outreach support service to children with Down syndrome in local mainstream schools, providing specialist assessment and consultancy services with families and in schools as well as delivering training conferences and workshops around the world.

Sue Buckley

Sue Buckley is a Chartered Psychologist with over 40 years of experience in the field of developmental disability. Sue studied Psychology at the University of Reading, UK and then went to Oxford, UK, for training in Clinical Psychology. She worked in the National Health Service for several years and moved to teaching in the Psychology Department, University of Portsmouth in 1975. Sue continued clinical work in the community establishing early intervention services in the 1970s and began research into the learning needs of children with Down syndrome in 1980.

She continued to teach and research in the University as well as establish the work of Down Syndrome Education International from 1980. She also worked on national and local government bodies tasked with improving services for individuals with disabilities. For the past 30 years, Sue has travelled widely to speak at conferences and training events and she is in high demand as a speaker. She has also published widely for families, practitioners and researchers and played a leading role in stimulating growth in research into the education and development of children with Down syndrome worldwide.

Sue is knowledgeable about most aspects of the development of children and adolescents with Down syndrome, but her special area of expertise is cognitive development, particularly language, literacy and memory development. Sue also has firsthand experience of many of the issues that affect families as the eldest of her three children, Roberta, has Down syndrome and was adopted into Sue’s family when she was a baby. Roberta is now an adult living with her partner in supported independent living facilities.

Speaker Biographies
DOWN SYNDROME SEMINARS
All sessions are 8:30 AM-11:30 AM
Down Syndrome Guild Conference Center
5980 Dearborn Street, Suite 100 Mission, KS 66202

Down Syndrome 101 for Educators
October 17, 2013 OR February 20, 2014
Are you an educator, professional or family member working with a student who has Down syndrome currently? If so, do you understand the unique learning profile of your student and how you can most effectively include, educate and encourage your student? Presenter will explore and provide information, resources, tips and strategies for the following:
- Common medical issues related to Down syndrome
- Communication issues and strategies for success
- How to improve social skills
- Processing time and memory issues
- Benefits of inclusive education
- Environmental issues which can hamper success
- Ways to adapt the curriculum
- Peer presentations to increase friendships
- Behavior intervention strategies
- Preferred teaching methods

Down Syndrome Specific Curriculum Supports
December 12, 2013 OR April 17, 2014
This educator led interactive seminar will help you better understand education support materials designed for learners with Down syndrome. Curriculums which improve reading, literacy, math, handwriting and memory skills will be covered. We will explore how these programs can be applied to your existing curriculum. Attendees will:
- Identify DS specific curriculum, programs and tools
- Discuss common core standards and how to apply
- Evaluate IEP goals and assignments
- Review unique learning profile of students with DS
- Learn helpful instructional styles that promote success
- Identify ways to motivate and engage students in the classroom
- Evaluate what works and what’s not working
- Learn how to modify and accommodate general education assignments to meet students needs

Effective Behavior Management Techniques for Students with Down Syndrome
September 26, 2013 OR January 16, 2014
Are you struggling to reach your student with Down syndrome? Frustrated that you spend a majority of your day managing behaviors instead of teaching? Do you feel your student is capable of more, but just can’t figure out how to get there? This hands on interactive seminar will provide practical strategies and real time solutions to help you work effectively and efficiently with your student who has Down syndrome. Attendees will learn:
- The benefits of providing appropriate processing time
- Tips for creating a high level of trust
- Creating a schedule and environment that works
- Planned ignoring techniques that work
- Strategies for dealing with the “top and drop”
- Helping your student be responsible for his own behavior
- Consequences and reward systems that make sense
- Techniques for managing non-compliance

Practical Solutions for Improving Speech and Communication in students with Ds
November 14, 2013 OR March 6, 2014
As a pediatric SLP and parent of a child with Down syndrome, I have a unique opportunity and perspective. Have you wondered why speech is so difficult for your student/child? Why they seem to know or understand something one day but not at a later date? Have you considered how memory and processing affect language learning and use? Are negative behaviors impeding progress? This presentation will highlight:
- Typical learning profile for student with Down syndrome
- Language supports and strategies
- Identify ways memory directly impacts language and learning
- Speech therapy considerations and techniques
- Interventions which prevent negative behaviors
- Language considerations when adapting curriculum
- Language facilitation strategies that can be used across all environments

RSVP FOR SEMINARS TO INFO@KCDSG.ORG OR 913-384-4848

Seminars sponsored by:
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/](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/](http://store.dseusa.org/).

Evidence-based practice: what does research tell us about the specific language and learning needs of children with Down syndrome

- 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.
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

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

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 motor skills through play and handwriting progress

The specific developmental profile associated with Down syndrome

- Significant risk of vision and hearing impairments
- Specific speech and language delays relative to non-verbal mental abilities

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
- 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*

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

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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 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 – CogniMD (Bennett, Holmes, Buckley 2013)
- Early speech perception and production difficulties could be causal as system has to tune to native language

Effects of poor verbal short term memory function
In other children with poor verbal STM
- Speech characterised by short utterance length
- Immature syntax/grammar
- Limited range of vocabulary
- Speech clarity issues
- Storage and processing of sentences
- Poorer reading and poorer maths


Executive functions now being studied
- 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 – Control impulses and behaviour at correct time/context. Emotional Control – Modulates emotional responses appropriately to situation.
- Plan/Organise – Anticipates future events/consequences.
- 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

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Implications for intervention and education

- 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

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Implications for intervention and education

- Progress with grammar is linked to total vocabulary size for children with Down syndrome – therefore teaching vocabulary is an important goal from early
- Speech skills start in first year – therefore intervention should start then – games to develop discrimination and encourage production of speech sounds
- Non-verbal communication skills predict talking (joint attention and pointing) therefore intervention should start in first year
- Gesture use can close the comprehension/production gap but we need more research on the proper use of signing

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Implications for intervention and education

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

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In summary

- Children with Down syndrome are visual learners
- They find learning from listening particularly difficult
- This affects learning to talk and it affects 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

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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

Comparison across domains

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Language and literacy -inclusion study

- Very significant gains in literacy (mean gain 3.3yr) and expressive language (mean gain 2.5 yr) 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

We can change the profile

- 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/296/

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 (2009) 10, 2, 86–103
- The Down syndrome behavioural phenotype: implications or practice and research in occupational therapy. Occupational Therapy in Health Care (2011) 25, 7-23

And a few more articles - preschool, primary and teenage profile papers
- Down Syndrome Research and Practice 9 (3) special section on the specific profile free at

Relevant research evidence is growing

- Whole journal issues devoted to Down syndrome – important review papers in 2007
- Mental Retardation and Developmental Disabilities Research Reviews 13 (3) 2007
- Important recent review papers and chapters on cognition (Silverman), language (Fidler et al., Roberts et al., Abeduto et al., education (Fidler & Nadel), reading (Grosen et al., Buckley, Snowling et al), social development (Barocci et al. Cebula & Whisnant)
- Gathercole & Alloway articles and books on working memory for teachers

References – speech, language and memory


References – cognition and education


Importance of full inclusion in changing the profile

**Overview**

- What is working memory?
- What do we know about its development in typically developing children?
- What do we know about its development in children with Down syndrome?
- What is the practical significance of working memory deficits?
- What can we do to improve working memory?

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**What is Working Memory?**

- **Working memory**: allows us to hold and manipulate information in the mind over short periods of time
- **Central Executive**: attention, the control of action, processing and problem-solving
- **Phonological loop**: stores verbal information in phonological form
- **Visuo-spatial sketchpad**: holds visuals and spatial information
- **Episodic buffer**: links with long-term memory and stored information – remembering routine activities in life

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**Effects of poor working memory**

- Limits in central executive – working memory system as a whole, now referred to as complex working memory – will influence progress in all complex tasks
- Limits in phonological loop function – verbal short term memory will directly affect vocabulary learning from infancy and through school years
- Poor WM capacity is a 'bottleneck to learning'
- Importance of automatization – once skills/knowledge over learned and automatic, working memory load reduced

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**Working memory is important for all children**

- 'Any task where the child is required to process new information and then transfer 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 at 6-7 years old (Year 2)
Working memory – academic progress

• Poor working memory places children at high risk for slow, academic progress, particularly literacy and numeracy
• Failure to follow instructions
• Problems with activities involving storage and processing
• Place-keeping difficulties
• Attentional problems – easily distracted; difficulties with concentration – working memory overload

Verbal STM in children with Down syndrome

• Verbal STM impaired relative to visual STM and relative to MA in children and in adolescents with Down syndrome – confirmed in many studies using digit span even when response required is point rather than say
• Also confirmed using non word repetition with lenient scoring (Laws 1998, Laws and Gurr 2004)
• Jarrold and colleagues conclude it is due to capacity limitations in the phonological store
• Central executive tasks too difficult for children (backward digit span)

Memory and Down syndrome

Research has shown that individuals with Down syndrome have specific deficits in the verbal memory domain.

This graph shows the results of a study comparing the performance of children with Down syndrome and typically developing children on a visual and verbal memory task.

Jarrold, Nance, & Lewis (2003)

Phonological loop functioning

Evidence shows that there is a basic impairment in phonological loop functioning in children with Down syndrome.

The phonological loop is a 2 component system:
1. Passive phonological store – material is subject to time based decay.
2. Articulatory rehearsal process that serves to refresh and maintain information in the store.

Links between speech, language and VSTM

• Phonological loop may have developed as language acquisition device (Gathercole)
• When learning a word sound pattern needs to be held and stored
• Recent research shows children with Down syndrome poor at learning detailed phonological forms of words. Learned meaning of new words but not fully accurate spoken form – very important study (Jarrold, Thorn, Stephens at Bristol)

Language learning and phonological loop

• Effect of poor phonological loop function on learning vocabulary greatest to 4-5 years of age in typical development (Gathercole)
• By 8 years the main route for learning new vocabulary (and grammar) is from reading
• Exposure to print and reading words in context important
• Children with Down syndrome use linguistic knowledge to support STM in non word repetition tasks to compensate for poor VSTM (Cain & Jarrold) – and other resources (Moose & Jarrold)
• They also use context to support grammatical deficits (Roth2014)
Maggie Vance – 2008 chapter

- Identifies that working memory development and spoken language development are inextricably linked
- Develops working memory skills in specific tasks where working memory is engaged
- Develop phonological skills to support phonological loop function – Phonological Awareness training
- Develop strategies to support recall - rehearsal, visual imagery
- Adapt the way material to be learned is presented

Rehearsal training – Sue Gathercole

- Rehearsal can be trained in non-rehearsing children
- By providing initial practice in overt rehearsal – the child says out loud the items to be remembered
- Once child can do this, encourage silent rehearsal
- Vocabulary teaching needs multiple exposures to new words presented in varying contexts in which the child is given abundant opportunity to practice immediate repetition as well as delayed recall and recognition of the novel sound structures
- Gathercole notes that research cited above that this does work with children with Down syndrome (Gathercole et al, 2001, Laws et al, 1998, Condron 1996 are paper can be found at: www.bowersandbowser.com)

Principles of working memory intervention

Almost all children with Down syndrome will have working memory problems.
- Advice to therapists/teachers from Gathercole/Allaway book – Working memory in the classroom
- Recognise working memory failures
- Warning signs include:
  - Incomplete recall
  - Failure to follow instructions
  - Place keeping errors
  - Task abandonment

Principles of working memory intervention

- Monitor the child
- Look out for warning signs and ask the child
- Evaluate working memory loads
- Heavy loads caused by lengthy sequences, unfamiliar and meaningless content
- Demanding mental processing activities
- Reduce working memory loads where necessary
- Reduce the amount of material to be remembered
- Increase the meaningfulness and familiarity of the material
- Simplify mental processing
- Restructure complex tasks

Principles of working memory intervention

- Repeat important information
- Encourage use of memory aids
  - Wall charts and posters
  - Personalised dictionaries
  - Counters, Numicon, number lines, multiplication grids, calculators
  - Memory cards
  - Audio recorders
  - Computer software

Principles of working memory intervention

- Develop the child’s own strategies to support memory
  - Asking for help
  - Rehearsal
  - Note-taking
  - Place keeping and organisational strategies

You will note that many strategies used to support ‘visual learners’ are on this list

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Developing memory skills - interventions

Research findings suggest 3 types of interventions may help to develop working memory:

1. Activities to improve phonological loop function
2. Activities to improve attention and to increase processing capacity
3. Activities to improve remembering of lists of items and associations between items, including categorization and rehearsal strategies

ALSO provide supports for remembering: visual aids, songs, use of context, routine

Activities to improve phonological loop function

- Compensate for hearing/listening difficulties
- Listening, discrimination, production of sounds
- Listening, discrimination, production of words
- Phonological awareness activities
  - Letters and sounds
  - Initial/final medial sounds in words
  - Word families
  - Blending
  - Segmenting

Activities to improve attention & processing capacity

- Sitting still
- Making choices – objects, pictures, referents, gestures
- Following instructions – one to one, in a small group, in the whole class
- Waiting for turn
- Reading book with adult
- Teaching new play/leisure skills

Activities to improve remembering number of items

- Hiding games
- Memory games
- Rehearsal training – pictures, numbers, words, sentences and spellings
- Auditory-verbal rehearsal
- Grouping or organisational skills (sorting, oddity tasks, memory tasks in categories)

Rehearsal training

Rehearsal training/auditory rehearsal
Other activities

- Delivering messages
- Giving the child instructions to follow
- Recall of activities
- Recall of stories
- Use of songs
- Games (e.g. pairs)
- Computer games

Memory training research - Down syndrome

Rehearsal training:
Rehearsal training studies have found that some improvements were made, but were only modest gain and were not sustained - and indeed gains did not transfer to working memory (Broadley et al. 1994; Cordina's 1994; Lewis et al. 1995; Hemsley, 2003) (see Table 2.1 & 2.2). However, gains were maintained over time (Broadley et al. 1994)

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

Cogmed Published Research

1. Adaptation 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 WM) (Holmes, Galler & Denham 2005)

2. When compared with Medication, Cogmed training showed greater benefits on all aspects of working memory (Children with ADHD) (Holmes & Galler & Denham 2005)
**Working Memory and the Brain**

Training induces significant increases in WM-related activity in the prefrontal cortex. (Tew et al., 2001)

Training results in changes in the density of cortical dopamine D3 receptors. (McNab & Varrone, 2000)

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**Pilot**

1. **Children with Down syndrome**
   - Group 1: No Intervention
   - Group 2: Intervention 1
   - Group 3: Intervention 2

**Main Study**

2. **Children with Down syndrome**
   - Group 1: Intervention 1
   - Group 2: Intervention 2

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**Measuring Memory (AWMA, 2007)**

- **Verbal STM**
  - Forward digit recall
    - Group 1: 5.8
    - Group 2: 5.4

- **Visual STM**
  - Backward digit recall
    - Group 1: 3.0

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**Video of Child from Group 1 at Time 3**

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**Raw AWMA Scores (pre and post training)**

<table>
<thead>
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<th>Group</th>
<th>Pre</th>
<th>Post</th>
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</tr>
<tr>
<td>Group 2</td>
<td>15.50</td>
<td>8.50</td>
</tr>
<tr>
<td>Group 3</td>
<td>15.00</td>
<td>8.75</td>
</tr>
</tbody>
</table>

---

**BRIEF-P – Executive Functioning Measure**

- **Working Memory**: Holds information needed for purpose of completing a task with an activity.
- **WM**: Moves items from one situation to another, solves problems flexibly.
- **Inhibition**: General inhibition and behavior at correct times/contexts.
- **Emotional Control**: Modulates emotional response appropriately to situation.
- **Flexibility**: Multiple future events/consequences.
- **Activation**: Indicates difficulty of cognitive processing and may require sufficient stimuli.

---

*All scores indicate proficiency in the range of normal function.*
Executive Functioning

<table>
<thead>
<tr>
<th>Group</th>
<th>Inhibition</th>
<th>Shift</th>
<th>Emotional</th>
<th>Working Memory</th>
<th>Mind/Shift</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>3</td>
<td>75.10</td>
<td>75.50</td>
<td>61.80</td>
<td>84.10</td>
</tr>
<tr>
<td>2</td>
<td>2</td>
<td>65.20</td>
<td>80.80*</td>
<td>57.00</td>
<td>71.70*</td>
</tr>
<tr>
<td>3</td>
<td>1</td>
<td>67.73</td>
<td>61.23</td>
<td>61.13</td>
<td>74.36</td>
</tr>
<tr>
<td>4</td>
<td>2</td>
<td>62.60</td>
<td>56.83</td>
<td>57.09</td>
<td>73.18*</td>
</tr>
</tbody>
</table>

BRIEF-P – Standardised Score Change

- Group 1: Score - 12.2
- Group 2: Score - 12.5

Summary

- Cogmed training was found to improve short term visual memory in 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 also completed Cogmed training at their local primary school.
- Game was subjective - children needed more frequent practice. The intervention programme is less intensive than ABA activities v 2.0.

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...
- Early 2014, phase 2 trials

Summary - targeting the profile

- Take account of auditory short term memory weaknesses
- Improve sound discrimination and production skills
- Practise words to improve the stored sound patterns
- Play memory games
- Support learning with visual materials, pictures and print, to reduce memory requirements
- Reduce the amount of material to be remembered
- Make it meaningful and familiar
- Restructure complex tasks/instructions - simplify

Supporting working memory

- Visual supports for...
  - Supporting verbal presentation of information
  - Understanding the activity
  - Supporting responding (writing, speaking) and assessment
  - Developing independent work habits (with a picture and work list to follow)
  - Increasing attention and participation
  - Improving behaviour – give socially appropriate strategy
  - Revision - of the lesson and specific objectives e.g. vocabulary that has been targeted for pupil
Children with Down syndrome compensate

Remember that studies show that children with Down syndrome
• Can use higher order skills such as inferencing from world knowledge and context to help overcome working memory limitations or ‘bottlenecks’ (Lavarato, Roch 2009)
• They can use mental imagery (de la Iglesia 2003)
• They can draw on their stored knowledge of words to support them in verbal short term memory span tasks
• Use of context can help with remembering information – use sentences

Useful books – recommended reading


Resources and references

• Buckley, S. & Bird, G (2001) Memory development for individuals with Down syndrome. 204 book online/shop

References

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Overview

Activities to support the development of spoken language skills

1. Profiles and norms
2. Teaching vocabulary
3. Teaching grammar
4. An example of a targeted language intervention programme
5. The pros and cons of sign after 5 years of age

Research update – language and grammar

- The pattern of vocabulary development is delayed but otherwise the same as in typical development.
- Expressive difficulties become greater with increasing age for children with Down syndrome.
- Vocabulary lags grammar, just as in typical development.
- Many teenagers are still 'telegraphic'—they use nouns, verbs and adjectives in their sentences but leave out joining words and word endings.
- The majority of teenagers understand much more than they can say—a source of frustration and leads to their understanding often being underestimated.

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

Language domains, VSTM and mental age over time

Variability in early vocabulary production

DSE longitudinal study in progress—preliminary data for illustration

<table>
<thead>
<tr>
<th>Month</th>
<th>Mean</th>
<th>Range</th>
<th>Mean</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>8</td>
<td>15-20</td>
<td>12</td>
<td>18-20</td>
</tr>
<tr>
<td>2</td>
<td>10</td>
<td>15-20</td>
<td>15</td>
<td>20-25</td>
</tr>
<tr>
<td>3</td>
<td>15</td>
<td>20-25</td>
<td>18</td>
<td>25-30</td>
</tr>
<tr>
<td>4</td>
<td>20</td>
<td>25-30</td>
<td>25</td>
<td>30-35</td>
</tr>
<tr>
<td>5</td>
<td>25</td>
<td>30-35</td>
<td>30</td>
<td>35-40</td>
</tr>
<tr>
<td>6</td>
<td>30</td>
<td>35-40</td>
<td>35</td>
<td>40-45</td>
</tr>
<tr>
<td>7</td>
<td>35</td>
<td>40-45</td>
<td>40</td>
<td>45-50</td>
</tr>
</tbody>
</table>

Note: enormous variability in early vocabulary for these children with Down syndrome. For comparison study of English typically-developing children at 22 months—the range is also very large at 70-165 words. (Stokes & Fiske)
Vocabulary development

Little normative data available
• Dasi Speech and Language Overview see http://www.dowmsyndrome.org/information/language/overview/
• Tables on both comprehension and production (Pennanen et al.)
• Information on reaching two word stage and on beginning to use grammar from our earlier studies
We are currently collecting normative data — it may change for each new generation
Vocabulary teaching is key to all aspects of language and literacy development

DSE research – children with Down syndrome

We have some data on sign and word development from two studies
• 1. Unpublished student project — data based on parent report using the MacArthur Communicative Development Inventories (CDI) collected in mid 1990s (Pennanen 2000)
• 2. Some preliminary data from the first data collection point of an ongoing longitudinal study of 40 children aged 16-42 months at the outset
Note: the data provides a guide to expected rates of spoken vocabulary development and is similar to other studies

Signers and non-signers (Pennanen 2000)

<table>
<thead>
<tr>
<th>Age months</th>
<th>Non-signers N = 133</th>
<th>Signers n=50</th>
<th>Words and signs</th>
</tr>
</thead>
<tbody>
<tr>
<td>CA (M)</td>
<td>mean std dev range</td>
<td>mean Std dev</td>
<td>range</td>
</tr>
<tr>
<td>12-23 (9)</td>
<td>10.7 12.7 0-38</td>
<td>87.0 50.7 47-144</td>
<td></td>
</tr>
<tr>
<td>24-35 (15)</td>
<td>28.1 34.9 5-125</td>
<td>73.3 62.1 25-193</td>
<td></td>
</tr>
<tr>
<td>36-47 (21)</td>
<td>129.6 171.2 4-199</td>
<td>157.6 71.3 31-349</td>
<td></td>
</tr>
<tr>
<td>48-59 (28)</td>
<td>147.8 157.9 11.8-451</td>
<td>229.1 128.2 88-505</td>
<td></td>
</tr>
<tr>
<td>60-71 (33)</td>
<td>205.7 181.4 8-549</td>
<td>182.6 95.1 90-314</td>
<td></td>
</tr>
</tbody>
</table>

Total productive vocabularies
Data from MacArthur CDI records collected in mid 1990s
NB cross-sectional data & large individual differences
Signs seem to give an advantage to 36-47 months, mental age of about 21-24 months. By 4 years no difference in productive vocabulary size — as Miller predicted and TDD data predicts

Changes in word and sign use over 12 months

<table>
<thead>
<tr>
<th></th>
<th>Group 1 14-18mo</th>
<th>Group 1 19-23mo</th>
<th>Group 2 14-18mo</th>
<th>Group 2 19-23mo</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sign only</td>
<td>50%</td>
<td>33%</td>
<td>47%</td>
<td>25%</td>
</tr>
<tr>
<td>Sign + word</td>
<td>33%</td>
<td>44%</td>
<td>31%</td>
<td>45%</td>
</tr>
<tr>
<td>Word only</td>
<td>9%</td>
<td>21%</td>
<td>22%</td>
<td>30%</td>
</tr>
</tbody>
</table>

NB preliminary data and considerable individual variation
Grp 1: 14-18mo
At 18 months CA: the children have words for 42% of vocabulary
At 23 months CA: they have words for 67%
Grp 2: 19-23mo
At 23 months CA: the children have words for 52% of vocabulary
At 28 months CA: they have words for 75% of vocabulary
Recent data once 200+ words, over 10% signs only
Sig = correlation between % signs and total vocabulary

Research summary: children with Down syndrome

• Signs increase total productive vocabulary from MA 14m to 26m — this would be about 4/5 years old (CA) for children with Down syndrome
• Typically developing children use signs from 14-26 months of age — then spoken words take over from signs
• Children with Down syndrome use gestures and signs for a longer time period
• The percentage of total vocabulary that is signed decreases with age even from 24 to 36 months CA
• At 4/5 years, most children with Down syndrome are decreasing use of sign and increasing use of spoken language (Miller; Berglund- Buckley)

Speech and language in the classroom

• Children learn to talk all day, every day so it is important to make a conscious effort to include children in conversations — and to listen to them
• Children with Down syndrome may start primary school with mainly one or two word expressive language and small vocabularies
• Data suggests at 5-6 years mean = 801 spoken words range 8-649 note DSE core vocabulary checklists = 800 words. TD children enter school with 5000+ words and have 800 spoken words at 30moths
• We would expect significant progress during primary and high school years
• They will learn from being included in conversation with peers and by listening to peers
• It is important to have targets for teaching new vocabulary and grammar and improving speech clarity worked on in parallel
1. Assessment of vocabulary is important

Vocabulary size predicts language development (see keynote - 200+ spoken words before grammar starts)
Keep a record of words understood, signed or spoken
Use DSE Vocabulary checklists 1, 2, 3 (900 word core vocabulary based on US research (CDR)
Informal assessment -
- If a child uses a word (or sign) appropriately
- If a child can act out the word or idea through gesture/role play
- If the child responds appropriately in the classroom
- If a child can point to a picture from a choice of pictures e.g. informally in lessons, in books, on the computer
- If the child's parent thinks he or she understands it

Choosing vocabulary to teach

- Curriculum topics
- Personal interests - motivating words to teach
- Liaising with parents/home
- Make it visual
- Use target words in sentences as well
- Promote vocabulary organisation - semantic links, knowledge networks
- Include social/emotional vocabulary - mental state verbs (thinking, knowing, remembering, wishing)
- Can still use matching, selecting, naming games
- Word webs/closed set activities

Word web

Example - he/she activity

Summary (vocabulary) - targeting the profile

Accelerate vocabulary comprehension and production
- Teach a target vocabulary
- Keep a record of comprehension and production of words
- Use augmentative communication systems, usually signs, to support comprehension and production of words
- Use reading activities to support the comprehension and production of vocabulary
- All curriculum topics provide new vocabulary

2. Grammar development

- Understanding grammatical concepts may begin when a child understands approximately 250 words
- Use DSE Sentences and Grammar checklist for assessment
Early grammar includes learning to use:-
- 'ing'
- Prepositions in/on
- Plurals
- Irregular past tense
- Possessives
- Articles a/the
- Regular past tense

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**Grammar development - research**

- Expressive grammar is a particular area of difficulty for children with Down syndrome.
- May be linked to speech difficulties.
- Kumin notes particular syntax difficulties (e.g., use of past tense, pronouns, negatives, etc).
- Syntax and length of utterances (MLU) continue to increase during adolescents and young adulthood (Chapman).
- Productive grammar is improved when elicited through narratives and visual supports — similar narratives to MA matched group (Miles, Chapman & Sindberg, 2006).

**Combining words - intervention**

- Modelling and imitation.
- Expansion.
- Use of signs.
- Pictures/props.
- Repetition and practice.
- Conversation diary.
- Sequencing cards/games.
- Focused personal books (e.g., plural book).
- Open-ended questions (e.g., tell me more...).
- Reading activities.

**Summary (grammar) - targeting the profile**

Accelerate mastery of grammar and sentence building.

- Encourage the use of complete sentences.
- Teach the grammatical markers.
- Teach word order rules.
- Teach function word grammar.
- Keep a record of comprehension and production of grammatical markers and sentences.
- Use reading activities to support the comprehension and production of grammar and sentences.

3. Use RLI reading and language program

- The language strand gives a structure for teaching new vocabulary and sentences.
- In themes — we know new language learning is supported by context for all children including those with Down syndrome (Roch et al.).
- Can be used to teach IEP and curriculum targets — often new concepts (e.g., hot/cold, living/not living).
- Small Texas pilot showed impressive language gains on RLI including those who were more delayed and non readers.
- Can be adapted for wide range of language abilities.

**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**

<table>
<thead>
<tr>
<th>Reading Strand (20 mins)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Reading easy level book</td>
<td>2-3 mins</td>
</tr>
<tr>
<td>Reading new instructional level book</td>
<td>5 mins</td>
</tr>
<tr>
<td>Sight word learning</td>
<td>2-3 mins</td>
</tr>
<tr>
<td>Letters, sounds, phonology</td>
<td>5 mins</td>
</tr>
<tr>
<td>Introduce new instructional level book</td>
<td>5 mins</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Language Strand (20 mins)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Vocabulary: introduce new words</td>
<td>5 mins</td>
</tr>
<tr>
<td>Vocabulary: Reinforce meaning of new words</td>
<td>5 mins</td>
</tr>
<tr>
<td>Expressive language: Use new words in connected speech</td>
<td>5 mins</td>
</tr>
<tr>
<td>Expressive language: Use new words in written language</td>
<td>5 mins</td>
</tr>
</tbody>
</table>
Language Strand

- Works on:
  - Introducing and reinforcing meaning of new words
  - Using the new word in expressive language
- Choosing the vocabulary
  - Used the DSE vocabulary checklists
  - Selected vocabulary that was:
    - Useful
    - Where possible manageable
    - Not necessarily completely new
    - Looked at both % know and % use ratings
    - Related to themes

Example from classwork

- Topic/theme: Electricity
- Target words:
  - Bulb
  - Socket
  - Bright
  - Dull
  - Switch
  - Press
  - On
  - Off

Introducing new vocabulary

Language Strand

1. Introduce and discuss new word: Provides written, spoken, and pictorial forms of new vocabulary
   - TA introduces word
   - Child says word
   - Child and TA discuss word using related photos
   - Child is shown flashcard
   - TA and child create a word web
   - Emphasis on relating to child's experience, and building a rich, multi-contextual understanding

2. Play a game using new word: Increases the depth of the child's understanding of new vocabulary by discussing word meanings in different contexts
   - Most of the games are based on:
     - Matching
     - Sorting
     - Demonstrating
   - Difficulty level can be adjusted according to the learning style and needs of the child
   - Emphasis on:
     - Multiple encounters
     - Using games as a springboard for more discussion about the meaning of the word
     - Having fun with the new word
Language Strand

Work on expressive language: Encourages the use of appropriate syntactic and pragmatic language skills

3. Child generates utterance containing new word
4. Child generates written sentence containing word
   - Guided by child's language level, aim to increase utterance length or complexity
   - Encourage/model/extend appropriate grammar
   - Scaffolded by TA
   - Independent writing tracing cut up sentences
   - Writing key words
   - Supported by pictures
   - Record kept in topic book

Expressive language film clip
**Topic book**

- The topic book has a number of purposes:
  - Communication with parents
  - Record of child's achievements
  - Record of what has been taught so far
  - Reference book – can be referred to and revised from
  - A source of 'easy' reading material

**See and Learn Language and Reading**

- A practical resource for professionals and families
- A language programme that focuses on receptive language, expressive language and reading development
- Teaches vocabulary on DSE Vocabulary Checklist 1
- Kits and apps available

**www.Specialiapps.co.uk**

**Special words** – first pictures and words from See and Learn Language and Reading program
- Adaptable, you can add your own pictures and words
- Available in many languages

**Special stories** – for creating personal books
- You can get the See and Learn Language and Reading books from our website to download into Special Stories
- Apps and software play to our children's strengths as visual learners

Very powerful learning tools but learning from app must be generalised to everyday use

**Bilingualism – Kay-Raining Bird studies**

- Case studies and experience tell us that individuals with Down syndrome can become competent bilingual
- Research group in Canada has shown that children with Down syndrome in bilingual environments
  - Do not show any disadvantage in their dominant language
  - Show similar patterns of acquisition in the two languages as other bilingual children

**SALT**

4. Use of sign with children with Down syndrome

No clear evidence of benefits – poor control groups in the few studies that are often quoted in favour of signing. We need much more sophisticated longitudinal research.

**Arguments in favour:**
- Strength in natural gesture
- Risk of hearing loss
- Working memory delays
- Risk of phonological issues
- Speech delays
- Increases attention
- Reduces frustration
- Increases quality and quantity of parent-child communication
- Improves general communication between child and parent
Cautions – real and possible

1. Signs cannot teach phonology and grammar
2. Signing is sometimes not stressed as augmentative – need to encourage sounds, words, lip-reading from first year of life
3. We do not know how children cope with attentional demands of sign plus speech or if signing changes how parents talk to children
4. Signs can reduce parent responsivity to child’s speech attempts
5. Signing may reduce child’s spoken word attempts – use of voice/sound/words need to be encouraged at all times
6. Research indicates that by 4-5 years, most children with Down syndrome are switching from majority of signed words to majority of spoken words – spoken language should be the focus from 4 years old for most children
7. By 4-5 years old, print is a better support for phonology and grammar

Summary (communication) – targeting the profile

Capitalse on good social interactive skills and develop them
• Be sensitive to all attempts to communicate
• Create opportunities for your child/teenager to make choices and to express him/herself through language
• Encourage the use of gesture to communicate
• Remember to listen and to wait to give the teenager a chance to organise their contribution to the conversation
• Use styles of communication that encourage the teenager to expand and develop their contributions
• Provide as many social opportunities as possible

Resources – practical books

• Buckley, S. (2001) Speech and language development – an overview
• http://store.diseusa.org/

Resources for language through reading

• See and Learn First Written words and First Sentences – may suit some school age children also See and Learn Speech http://store.diseusa.org/see-and-learn
• New See and Learn kits in 2014 for speech and language – in kit form and as apps, software programs

Special apps

See and Learn apps for apple and android in UK and USA http://www.specialapps.co.uk/en-go/

Special Words – teaches See and Learn vocabulary and you can add your own pictures and words
Special stories – enables you to make personal books with photos and text – it is easy enough to be used by children. Developed by ICT experts who also happen to have a son with Down syndrome - Both apps have won awards

References

References


The RLI handbook and resources

- 144 page handbook
- 2 DVDs of illustrative video clips
- CD-ROM containing assessment tools, example lesson plans and sample teaching resources
- Cost £80.00

See and Learn - early intervention materials

- Visual supports for learning
- Language and reading from first words to sentences
- Speech from sounds to words
- Number coming firstly
  http://www.seeandlearneducationalresources.com/
- Further information
  seeandlearneducationalresources@gmail.com
  blogs.seeandlearn.org
  @seeandlearn

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Supporting speech development – school years SLT

Speech development
- Starts early in typical development
  - In typical development, children are learning to discriminate sound in the first year of life – tuning in to native language
  - High incidence of hearing loss
  - Phonological difficulties
  - Verbal short term memory difficulties
  - Poor auditory processing
  - Differences in anatomy and physiology
  - Research shows sound production ability influences first words in language development (Shed-Gammone 2011)
  - Speech difficulties likely to influence both vocabulary and grammar learning and production

Links between speech and Verbal STM
- Phonological loop in working memory may have developed as a language acquisition device (Baddeley, Gathercole 1998)
- When learning a word, sound patterns needs to be help and stored
- Children with Down syndrome are poor at learning detailed phonological forms of words (J erkel et al 2008)
- Speech sound development influences development of phonological working memory (Keren-Portnoy et al 2010)

What the research says about speech

Children with Down syndrome
- Babbling – mixed information in the research
  - more alike than different
  - babble period is much longer and transition to words takes longer
- Phonology – mixed information in the research
  - Barbara Dodd – emergence of phonemes follows typical development
  - Libby Kumin – different emergence of phonemes
  - both agree – huge variability and lots of inconsistency in production
  - Recent study shows delay in phonological development increasing from stage of first 10 words – about 2 years of age (Sokol, Fey 2013)

Intelligibility
- 95% of individuals with Down syndrome have speech sound production difficulty (Kumin 2006)

Assessment of speech
- Due to inconsistencies, formal articulation tests are not a good indicator of mastery for children with Down syndrome and therapists should observe sound production in play and use of sound in everyday social situations
- Articulation/phonology work should remain a high priority through childhood and adolescence as well as focus on segmental and suprasegmental aspects of speech
- Fluency, voice, prosody – have all been described as impaired with stuttering and or stuttering 10-45%, studding 5-10%
**Intervention studies**

Barbara Dodd, Ciotha Ni Cholmain: small studies with +ve outcomes  
Rote practice and repetition – core vocabulary approach  
Parent education/involvement  
Certain phonological processes highlighted  
Results  
- all children in the programme showed a change in their phonological system within the first two weeks  
- it is possible to accelerate the phonological development and Ni Cholmain reports increase in MLU suggesting speech is holding back grammar

---

**Intervention program**

- Discrimination and production of single phonemes  
- Combining phonemes – CV and CVC  
- Practising words  
- Practising multi-syllable words  
- Practising sentences  
- In assessment this is what I would work through whatever the age of the child/adult  
- Dodd suggests we are too accepting of child’s poor production so errors persist which could be corrected  
- Speech is a motor activity – motor skills only improve with practice and feedback

---

**Intervention**

Discrimination  
- challenging the auditory system  
- noticing subtle changes in sound  
- refining the listening system  

Practical activities  
- noticing differences between similar sounds  
- rhyming words/similar words

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**Film clip – discrimination – 2-1/2 years**

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**Intervention**

Production practice  
Based on individual child’s needs  

Practical activities  
- single sounds/sound cards  
- symbolic sounds  
- consonant+vowel combinations  
- simple words  
- syllable marking – 1, 2, 3, 4 syllable words
Film clip – syllable marking – 4 years old

Intervention

Auditory bombardment – repetitious listening and for production of a particular sound – in isolation or in a word
• draws attention to sounds in isolation, syllables, and words
• production practice of sounds in isolation, syllables and words

Practical activities
• sound books
• sound boxes
Order of sounds and words is child-led by child’s production

Some evidence this approach is effective for children with Down syndrome and can improve phonology quite quickly (see Dodd, Nill, Chalmers ref) See and Learn Saying Words kit based on this work.

Film clip – auditory bombardment – 3 yr old

Intervention

Sorting by initial sounds in words
• listening practice – draws attention to initial sounds in words
• production practice – draws attention to sounds in words

Practical activities
• sound books/boxes – sorting by initial sound
• I spy….. Game

Film clip – initial sounds in words – 4 years old

Initial sounds in words – listening and production
Intervention

Letters and sounds
- listening and production practise
- foundations for phonics
- visual prompt for production

Practical activities
- sound cards and plastic letters
- matching letters in words
- sound blending – listening and production

Direct link with foundations for reading and supported by study by van Bysterveldt et al (2010) – taught PR and letter sounds and positive affect on speech

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Film clip – CVC – beginning blending

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See and Learn Speech

See and Learn Speech aims to improve speech discrimination skills and develop clearer speech production
- Structured step-by-step program designed specifically for young children with Down syndrome (from 4 months to 7 years old)
- Materials and guidance for activities (suitable for home, group and therapy setting)

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Six steps (packs):
- Step 1: playing with sounds
- Step 2: putting sounds together

Available
- Step 3: saying words
- Step 4: saying more words
- Step 5: saying later words
- Step 6: saying syllables in words

2014 – in kits and apps

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See and Learn Playing with Sounds

- Listening to sounds and becoming familiar with sounds
- Hearing the differences between sounds (discrimination)
- Producing sounds in isolation

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See and Learn Putting Sounds Together

Resources:
- Picture cards representing consonant-vowel combinations (e.g. bik, key, tea, pea, sea)
- Picture cards representing syllabic sounds (e.g. breer, bomin, choo, choo)
- Record sheets

Activities:
- Using sound cards and picture cards as visual cues to prompt production of sound combinations

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Reading activities support speech

- The sentences in See and Learn First Written Words, First Sentences and More Sentences can be used to help children practice producing sentences. They follow the developmental language order so start with early two-word sentences and progress to longer sentences.
- Reading activities can provide a valuable support for practicing spoken language. Many children, including those with Down syndrome, speak more clearly when they read – probably because they do not have to construct the language themselves – so some processing load is reduced leaving more available to support speech production.

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Oral motor skills

- Little is known about the link between oral-motor skills and speech skills. There is no evidence that interventions that target non-speech oral-motor skills benefit speech production.
- However, some basic oral-motor skills are necessary for speech e.g. jaw closure, lip rounding and tongue retraction.
- Any activities that promote these skills may be helpful and certainly won’t be harmful.
- Research in progress on this issue in UK (Alcock, Goody)

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Feeding

- Promoting strength and mobility of the oral-motor structures

Practical activities

- Spoon feeding – spoon straight in and straight out
- Spoon feeding – putting food into cheekpockets to promote tongue lateralisation
- Texture variety – moving on from puree
- Bite and dissolve food – chewing
- Seating position – promote stability

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Fluency

- Contributing factors
  - Physiological – genetic predisposition, processing; speech motor skills; reduced ability to link target to motor plan; structural issues; later milestones
  - Linguistic/language – uneven language development; transition from lexical to grammatical based system; word length and complexity; word finding difficulties; dyspraxia
  - Emotional – low self esteem; anxiety and/or excitement
  - Environmental – communication demands, peer pressure; interaction style; reactions of others
Developing literacy skills – school years SLT

Reading for children with Down syndrome

- Reading is an important and worthwhile goal for all children.
- Many children with Down syndrome are able to develop some level of reading ability.
- Literacy attainments vary widely with some 10 year olds able to write short stories unaided and some learning a sight vocabulary.
  - Many of the highest achievers were introduced to reading at an early age.
  - Some children ‘take off’ with reading as teenagers.
- Reading shares reciprocal relationships with speech, language and working memory development.

The benefits of developing reading

- Literacy is an important goal in itself.
- In addition:
  - Learning from listening is difficult for children with Down syndrome, learning from looking is easier.
  - Printed words seem easier for them to remember than spoken words.
  - Reading activities can teach new vocabulary and new grammar.
  - Reading supports spoken practice of words and sentences as children read aloud or imitate.
  - Spelling and phonics work can support articulation and phonology so improve speech intelligibility.
  - These benefits are true also for non-readers (i.e. supported reading activities).

Overview

Literacy teaching – key components
Should be comprehensive:
1. Book reading
2. Sight word learning
3. Letter sound knowledge
4. Phonics and phonological awareness
5. Comprehension
6. Language
7. Spellings and Writing
8. ICT to support literacy learning
9. General guidance

1. Book reading

- Experience with a range of reading books
- Books with words – not picture books
- Personal books: personal books are about the students: life and interests as well as targeting the school curriculum.
  - These books should be:
    - Written as if the child has written it themselves
    - Written at an appropriate language level for the child
    - Created together with the child to build understanding
- Personal books support reading comprehension and teach language - new words learned faster in personal stories (Messier, Kucirkova in press)

Personal book (film clip)
1. Book reading
- Formative assessment – useful for gauging levels and progress, and for monitoring reading behaviour
  - Book bands/levels
- Support comprehension and language
  - Pictures
  - Vocabulary
  - Discussion/questions
  - Prediction/sequencing/summarising
- Repeated readings – promote fluency and comprehension and success/enjoyment
- Supported and independent reading
- Send books home – communicate about expectations

Supported reading

2. Sight word learning/whole word reading
- Often a strength in Down syndrome
- Many English words cannot be sounded out – need to be learnt by sight
- Pre-school children – we start whole word/sight word reading activities when:
  - a child understands 50–100 words
  - is able to match and select pictures
  - this is usually around 2½–3½ years of age
- Older children/adolescence – same principles, adapt resources and activities
Start with sight words, personal books and reading for meaning
Sight words – teaching activities

- Matching, selecting, naming

  football  football  play  play
  you  you  want  want

Sight words – teaching activities

- Word walls
- Character tubs
- 'Words I know' & 'Words I am learning'
- Physical games
  - Words on a wall
  - Flashcards around the room
  - Flashcards on the floor
- Write/trace word – sand, paint, pencils
- Pairs games (pelmanism)
- Pictures

2. Sight words – which words?

**Beginning readers: choose words to make sentences**
- Personal and motivating
- Words child understands
- Family names
- Character names
- High frequency words
- 'Tricky' irregular words
- Words from reading books
- Keep a record

2. Sight words: use in sentences

- Sight words can be used to build sentences - simple grammatically correct sentences.
- Ensure sentences can be read and understood
- Always read the words and sentences with the child while they are learning – that is use errorless learning techniques to support success.
- Make personal books to illustrate the sentences.
- Use the words children learn as sight words in expressive language - sentence including the word in appropriate context

Film clip – word in simple sentences

Using sight words in expressive language
3. Letter sound knowledge

- Important for phonics
- Individual sounds (b, t, s, ...) digraphs (oo, ay, ee, ...) and clusters (sl, sn, dr, cr, ...)
- Structured sequential progression
  - Map on to phonics progression e.g. phonics program used in school for other children
- Actions can help learning
  - Aim to progress to stage where actions are not needed
- Can be taught using similar principles/activities as used in sight word teaching (matching, selecting, saying)

4. Phonics and phonological awareness

- Listening to sounds and linking letters and sounds
- Listening to sounds (phonology)
  - Use visual supports where helpful (pictures/objects)
    - Rhyme
      - Rhyme matching/pelmeni game, rhyme oddity, rhyme production
      - Work with picture/objects/word cards
  - Phrases
    - Designating initial/final sounds
      - Matching and sorting games ask child to match pictures or objects based on starting or ending with the same sound
      - Visual/etonics: ask child to find objects in a picture that start/end with a certain sound
    - Play 'I spy' (something/begging/ending with)
    - Listen to spoken word pairs: do they start/end with the same sound or not?

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I-Spy with picture support (film clip)

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4. Phonics and phonological awareness

- Phonemes (continued)
  - Blending
    - Use phonemes the child knows
    - Use a toy to do 'sound-talk': e.g. What word is the toy saying? 'c-a-f'
      - Use picture for support (cat, dog, far, ... child points to correct one) but move on to littering only as child succeeds with pictures
    - I-spy with a few objects e.g. I spy with my little eye a 'p-e-n'
  - Segmenting
    - Use phonemes the child knows
    - Use a toy to do 'sound-talk': child does the sound talking - TA says, 'Can you say 'cat' in sound-talk?'; child says, 'c-a-t'
    - Phonetic frame: ask the child to sound out a word (e.g. dog) and put a coin/counter into the frame each time a sound is said

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Oral blending (film clip)

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Film clip - segmenting

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4. Phonics and phonological awareness

- Linking letters and sounds for reading
  - Repeat the ‘sound-talk’ and phonic frame activities but using magnetic letters. E.g. Give child the letters for ‘cat’, (plus 1 or 2 extra) and ask them to spell out ‘cat’
  - Spread out the magnetic letters that spell a word, ask child to say each letter; slide the letters gradually closer to one another; the child says the letters faster together until they blend them into the whole word
  - Give them flashcards with words and ask them to sound them out (d-o-g), then put them together to form the word (dog)
  - Model sounding out whenever a child gets stuck on reading a word in their reading books

5. Support comprehension

- Utilise visual strengths
  - Mental imagery techniques e.g. teaching children/young adults to picture stories in their minds when answering questions
  - Using picture cues to visualise segmented sentences, full sentences, short stories
  - Using picture cues to discuss feelings, make predictions, explain causal events, etc.
  - Write questions and provide answer choices

- Support vocabulary and grammar
  - Difficult new words and/or contexts; word tense etc.
  - Direct teaching
  - Provide other examples, model and demonstrate, etc.
  - Formulating sentences with flashcards

5. Support comprehension

- Retelling/summarising/sequencing activities
- Predicting/inferring
  - Use of modelling and scaffolding
- Questioning
  - Answering questions and formulating questions
  - Natural discussion
  - Expressive demands – support e.g. give choices, picture selection tasks, written questions, etc.

- Strategies
  - Look-back
  - Using context (including pictures)
  - Link to world knowledge and personal experience

Comprehension support during reading

Matching sentences to pictures
6. Language skills

- Use reading activities to support vocabulary and language development
  - As you come across new word meanings and grammar/morphology in books
  - Matching words in a sentence
  - Ordering words to form a sentence
  - Choosing words to make own sentence e.g. from a closed set, personal dictionary, word board
  - Filling in the missing word
  - Writing with support e.g. recall of ideas
  - Independent writing
  - Using words in spoken sentences
Making a sentence with word cards

7. Teach spellings
- Spelling work will continue throughout school and can be targeted alongside phonics e.g. blending/segmenting word families
- Teaching spellings can support articulation and phonology and therefore improve speech skills such as clarity and intelligibility. Links between the written and spoken form may need to be specifically taught.
- Developing spelling can also improve understanding and expressive language e.g. grammatical markers

Examples of spelling activities
- Practice writing alongside reading from the start as this will draw attention to letters (as well as help develop handwriting).
- Rehearsal method – look, cover, write, check.
- Reduce handwriting demands e.g. magnetic letters, spelling software.
- Using word families to support learning spellings e.g. ‘at’ or ‘en’ words
- Learning phonic rules
- Reading scheme words/sight vocabulary words
- High frequency words e.g. curriculum and topic words

Film clip – spelling word families

8. ICT to support literacy learning
- Look for good software to support literacy learning
  - Visual support
  - Motivation
  - Non-verbal mode of response
  - Immediate feedback
  - Opportunity for practice
- Guidelines for choosing software:
  - Avoid spoken or written language that is too complex
  - Appropriate speed of activity – presentation and response
  - Style and size of font
See some software links in resources

8. ICT
- There are fewer packages for high school students which are designed at an appropriate language stage and are equally age-appropriate.
- For children who are having difficulty with spelling and typing, programmes that provide word choice are useful e.g. Clicker.
- Students at secondary level often find typing easier than handwriting and access to a laptop and general programmes such as Word can be helpful.
- Computers are often motivating and activities such as email can target literacy and be fun!
9. General guidance

- Make reading fun
  - Use a variety of activities and/or presentations
  - Be enthusiastic!
  - Start sessions with something the child can do
- Use consistent vocabulary to support understanding and recognition
- Use errorless learning – children with Down syndrome can be sensitive to failure and we want to guarantee their success and motivation
- Progress at the child’s pace - slower steps and perseverance
- Practice and repetition – (RLI and Allers et al. 100 sessions or more)
- Monitor and record achievements and progress
- Promote strategies for independent literacy with appropriate support
- Home-school link
- Continue literacy teaching throughout school

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RLI – Reading and language program

- We have designed and evaluated a reading and language program which incorporates these principles
- Progress was significantly faster on key reading and language measures on the programme – see (Burgoyne et al. paper in resources list)
- RLI Handbook and Resources published with video
- Over the last school year we implemented RLI in a pilot project in Texas – can be used in US schools with positive outcomes for both reading and language
- Training educators across Texas at present and RLI accredited US based trainers
- Web-based training available

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RLI 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

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Session Structure

<table>
<thead>
<tr>
<th>Reading Strand (40 mins)</th>
<th>30 mins</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reading assessment level book</td>
<td>5 mins</td>
</tr>
<tr>
<td>Reading new instructional level book</td>
<td>5 mins</td>
</tr>
<tr>
<td>Sight word learning</td>
<td>5 mins</td>
</tr>
<tr>
<td>Letters, sounds, phonology</td>
<td>5 mins</td>
</tr>
<tr>
<td>Introduce new instructional level book</td>
<td>1 min</td>
</tr>
<tr>
<td>Language Strand (20 mins)</td>
<td>5 mins</td>
</tr>
<tr>
<td>Vocabulary: Introduce new words</td>
<td>5 mins</td>
</tr>
<tr>
<td>Vocabulary: Reinforce meaning of new words</td>
<td>5 mins</td>
</tr>
<tr>
<td>Expressive language: Use new words in connected speech</td>
<td>5 mins</td>
</tr>
<tr>
<td>Expressive language: Use new words in written language</td>
<td>5 mins</td>
</tr>
</tbody>
</table>

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Concluding comments

- All children with Down syndrome will benefit from reading activities
- Reading makes language visible and tangible
- Print makes knowledge permanently available for inspection and reflection
- These points are important for children with memory and language delays who are less able to hold and manipulate knowledge ‘in mind’
- The teaching methods are simple and are equally relevant in special or mainstream classes

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Resources – some software ideas

Clicker 6 software – UK and USA

Widget software and apps – using symbols (Don Johnston US)

Inclusive technology – UK and USA
http://www.inclusive.co.uk/

Specialiaapps – See and Learn apps ipad and android UK and USA
http://www.specialiaapps.co.uk/en_gb/
Introducing RLI

Further information about RLI:
- DSE website: [http://dsunet/YC3L](http://dsunet/YC3L)
- Scientific paper: [http://dsunet/7VR9d](http://dsunet/7VR9d)
- Online event: [http://dsunet/0V1Y](http://dsunet/0V1Y)
- New RLI blog: [http://dsunet/3MMy3](http://dsunet/3MMy3)
- RLI email group: [http://dsunet/RA078](http://dsunet/RA078)

RLI Handbook
- From UK store: [http://dsunet/YR16L](http://dsunet/YR16L)
- From US store: [http://dsunet/XpY1G](http://dsunet/XpY1G)

See and Learn - Early Intervention Materials

- Visual supports for learning
- Language and pre-reading from birth
- Sounds from words to words
- Number counting firmly
- Further information: [http://www.alphabetsouth.co.uk](http://www.alphabetsouth.co.uk)
- Blog: [www.buckley.org.uk](http://www.buckley.org.uk)
- Twitter: @Buckley

Practical Guides and Resources

- Odlawi, P. Teaching reading to children with Down syndrome: a guide for parents and teachers. Woodbine House (CD rom of resources)
- Down Syndrome Issues and Information series – books on reading (Buckley, Bird – to be updated 2014)

DSE will be publishing more practical materials to teach letter sounds, blending and phonics in 2014 – sign up to e-mails to stay informed.

References to RLI and Blending Study


While the Handbook is intended to provide all the information needed to implement the intervention, we are continuing to support the roll-out in schools with training, web seminars and blog.

References - Literacy and Down Syndrome

Pragmatic skills

- Intention
  - Requests
  - Proposals
- Sharing information
- Discussion
  - Considering
  - Supporting
  - Maintaining topic
  - Changing topic
  - Resuming or reforming topic
- Narration
- Language for taking a story or experience

Pragmatic skills — typical development

- Early non-verbal turn-taking forms the basis of turn-taking in conversation
- 5-12m – intentional communication
- 2y – request information, answer questions
- 3y – maintain conversation topics
- 4y – talk about people and events, more distant in time
- 5y – maintain topic, 80% of the time
- 7-9y – can understand other person’s point of view, can repair conversation breakdowns
- 12y – narratives include thoughts and feelings about events and resolutions

Pragmatic skills — Down syndrome

- Appears to be a relative strength
- Progress through the same stages in a similar order
- Pre-linguistic stage – research findings are mixed
  - Some have found similar rates of commenting, lower rates of requesting (Mundy)
  - Commenting and requesting are both linked to better language outcomes (Toher)
- Children and teenagers may be less likely to introduce a new topic and may elaborate less to maintain topic
- However – speech problems and intelligibility are a major influence on their conversational skills — not all pragmatic difficulties

Narrative skills — Down syndrome

- Relative strength when visual supports are used
- Children with Down syndrome used same themes, salient events and plot as children matched for cognitive level and language comprehension in narrative reports of wordless video events and story books (Boudreau, Chapman 2000, Miles: Chapman 02) but used less complex language to share this information
- When stories presented verbally, without picture support, the amount recalled was less than matched children (KrB, Chapman Schwitz)

Repair and social perspective taking

- Able to repair when asked for clarification
- Less likely to take in the needs of the listener
- Weakness in referential communication, related to expressive language deficits
- Teenagers less able to guess what other people know – related to knowledge base?? (Abbeduto)
Need for those around them, peers, family, staff, to understand their difficulties and to compensate
Supporting social use of language

(adapted from Kumm - Classroom Language Skills for Children with Down Syndrome, Woodbine House)

- Eye contact - cue and reward for increased eye contact
- With physical prompts
- Picture of wide open eyes
- Facial expression - need to match what is being said
- Dictionary of facial expressions
- Comment of emotions and characters - books/TV
- Mirror practice

Supporting social use of language

- Requests - use a picture for communication
- Play letter cards
- Model alternative actions
- Class 'tea-tasting' time - everything is communicated symbolically
- Requests
- No no-nuggets (cues, etc) - counter in development, there must be reason on
- RE-questions - open ended
- Interviews
- Ask the class questions in a graph - e.g. 'something you can eat'
- Ask family who they want to talk to first
- Mystery games - e.g. 'An object is on the back - have to ask questions and guess'
- Scripts
- Requests for objects
- Requests for permission

Supporting social use of language

- Knowledge of adjectives of difficulty
- Matching - get the same item
- Beginning cards
- Beginning
- Conversation skills
- Photos
- Photos at home
- Token exchange games - words on same topic
- Following form in DSH
- Tokens - shared
- Photo books
- Word cards
- Word cards - shared
- ABA plans

Supporting social use of language

- Skills variants - the way people communicate in different situations
- Not always a game
- Scripts - potential road to different questions
- Communication breakdown - repairs
- Increase requests for clarification
- Speaker takes more responsibility for breakdown - 'I can't say clearly' - to increase confidence in questions
- Prosopagnosia - background knowledge and prior experience that the listener needs to bring to a conversation
- Rehearsal
- Describe something very similar to the listener
- Explain why it is the first time you have played it

Down syndrome and ASD

- ASD (Autistic Spectrum Disorder) combines two types of diagnosis
- Autism disorder ASD - not otherwise specified (PDD-NOS) - more inclusive diagnosis
- For children with DS, ASD dual diagnostic statistics vary, but a recent study indicates and incidence of approximately 38.2% (DiGuiseppe et al. 2010) but estimated true for total population 1%
- With more severe cognitive and sensory impairment - not typical ASD
- 16-55% of children with DS show physical neurobehavioral symptoms such as hyperactivity and impulsivity, oppositional and disruptive behavior or stereotypic movement and autistic features

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, DiGuiseppe, Hapburn, Fildes
- 133 children, aged 2 to 12 years. Modified Checklist for Autism in Toddlers (M-CHAT) younger children - Social Communication Questionnaire for older children followed by the ADOS and ADI.

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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 28-30 months. Castillo et al (2008)
- We need to understand the ‘ASD’ profile seen in children with DS in more detail – treatments could be different (Moss and Howlin)

Features of DS and ASD

- Significantly greater cognitive impairment – 87% have IQ below 40
- In the general population, 75% of people with ASD have IQ below 20
- 80% male; some studies but Moss (UK study) no gender diff
- In the general population, 4:1 ratio of male to female
- Up to 50% show a regression in language skills
- In the general population, 20-50% of children show regression of other language or social skills on both
- But new data appearing – Moss et al. UK and Colorado group suggest it is not typical autism. Continue to be more socially engaged. Moss – repetitive interests, rituals, preference for routine, attachment to objects same in non-autism DS group. Giustepapi paper – cautious on diagnosis.

Is it autism? Colorado team conclusions

- They say that these children usually present with significant problems in communication and repetitive behavior; whereas their social style demonstrated less recency than expected for their overall developmental level; core social relatedness was not impaired. The question remains whether these children truly had an ASD, or whether cognitive, temperament, attention, and motor factors combined to influence reciprocity and communicative development. Dufresne et al. p. 188.
- Is it executive function deficits? (i.e. in planning, shifting attention, perseveration, cognitive inflexibility) which affect social and communicative functioning - many items on screening tools tap aspects of executive function. P. 189

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

Features of DS and ASD

- Usually early diagnosis on basis of repetitive behaviours or sensory issues despite social/emotional relatedness
- Many children with Down syndrome show repetitive behaviors (e.g. hard flapping) in the absence of any social or communication impairments
- Many children with severe/profound delay get labeled as ‘autistic’
- DSE longitudinal study in progress to explore the early predictors of autistic behaviors

Aims of longitudinal study

- Track changes in behaviors diagnostic for autism
- Track range of onset of these behaviors 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
- Toddler Temperament Scale
- Detailed sign and spoken language records
- Early Support Developmental Journals for babies and children with Down syndrome
Findings

- Number of children at risk decreases (15 to 9 to 3 by 5-6 years)
- The majority of children 'at risk' do not lack core social interactive skills at Time 2 – they play, show and attract attention to activities
- This is not typical 'core' autism and we need to consider what this means for interventions
- Repetitive behaviours decline with age
- Note that 'stare and wander to no purpose' and 'oversensitivity to noise' are common (50%) – and not specific to the 'at risk' group

Implications

- We need to further analyse our findings and follow the group further
- RUT – the majority of children 'at risk' do not lack core social interactive skills at Time 2 (differ to Colorado item data – may be intervention effect for our group?)
- 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

Early signs or risk factors

- 'Red flags' are based on observation of non-DS children who later develop ASD
- Failure to sit by 8-12 months for children with DS this could be 2 years old
- Lack of communicative gazing and pointing – joint attention
- Increased rocking of objects
- Increased self-stimulatory behaviours
- Increased atypical motor examinations
- Increased passivity ‘being too good’
- Increased irritability
- Allergic sensory responses
- Hypersensitivity to sound
- Hypersensitivity to visual stimulation

Diagnosis of ASD

- A detailed assessment of cognitive level
- A detailed assessment of receptive and expressive language
- A developmental history with an Autism Diagnostic Interview
- Observation of the child in structured and unstructured settings – with a standardised autism diagnostic schedule
- Screening for medical/genetic conditions
- Consideration of other relevant psychosocial factors

Features of successful intervention - ASD

- Structured teaching programmes with emphasis on visual cues – for predictable and understandable environment; to limit confusion and distress
- Family-centred interventions – not just child-centred
- Development of social communication and play activities – especially with peers
- Acknowledge that behaviours reflect child's behaviour repertoire and communication skills – so focus on skill enhancement
- Understand that obsessions and rituals
- Play a role in reducing anxiety
- Are powerful sources of excitement and reinforcement

Intervention

- Advice for families
  - Discuss your child's additional needs in the family
  - Recognise the extra demands that they make
  - Ask for extra services including respite care
  - It may help to link up with other families in the same situation
  - A child with Down syndrome and autism should receive services from autism specialists and also specialists in Down syndrome (as yet mostly nonexistent?)

There is as yet no evidence in literature about response to treatment or educational strategies for children with Down syndrome and autism.
**Intervention – Complex needs**

- Management of severe hearing loss, vision and other sensory issues
- Develop a daily routine and visual timetable to provide structure
- To allow child to anticipate what is expected
- Reduce anxiety
- Focus on encouraging communication skills
  - This may be in very small steps – any new skills will help
  - Remember to offer choices
  - Remember to respond to all attempts to communicate

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**Intervention – Complex needs**

- Encourage children in play and activities with partners as much as possible
- Even in experiences in sensory play/rooms can be with others
- Try to limit time spent in repetitive activities so that they do not “take over”
- Use routines to help (e.g., clear expectations for behaviour)
- Use simple, clear and consistent language to maximise learning and understanding
- Be calm in all your interactions
- Keep emotional expressions to a low intensity
- Displays of emotions that are sensed but are not understood will increase children’s anxiety

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**Intervention – Complex needs**

Encourage participation in meaningful activities at home – household chores, responsibilities, care of pets
- Children with very limited self-occupation or play skills may be able to help with these, thus reducing time spent in repetitive or “self-stimulating” activities
- Examples – laundry is laundry bin, pulling up duvet to make the bed, taking dishes to kitchen or maybe in dishwasher, simple washing, rinsing or other cleaning tasks, watering plants, sorting items, getting cups out for drinks for people, handover use
- Some of the meaningful tasks will also encourage independence and self-help
- Examples – brushing hair, pouring cold/liquid/brink, wiping own face, washing, dressing, sequences of activities for personal care for toileting or managing confidence

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**Intervention – Complex needs**

- Many planned activities and more supportive leisure activities and regular care
- Going out with adapted equipment
- Driving
- Chores
- Tailoring/active play
- Housekeeping
- Cooking
- Washing the car
- Digging and other activities in the garden
- Cooking activities
- Washing, washing up
- Ball games/sport activities

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**Intervention – Complex needs**

Engage children in play activities with partners as much as possible – recognising that left alone they will not be able to make progress
- Cause and effect and pretend play toys with younger children
- Play with simple construction equipment
- Extend range of play with balls, or water, or particular textures/materials (sand)
- Colouring
- Arts and craft
- Music – operate CD player, musical toys or instruments
- Use of ICT, camera
- Watch favourite TV programmes together

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**Engagement in the community**

- Many of the activities mentioned previously can be through clubs or shared activities with people with and without learning difficulties
- Explore community opportunities with a social worker, if one is available to you
- Use Personal Centred Planning approaches – especially for older children and young adults
- This will lead you into methods for achieving goals
  - Circle of friends
  - Peer support – in and out of school
- Use visual methods to facilitate the child’s choices, as appropriate – telling mats
- Explore community opportunities with the child’s school
Structured programmes for autism

- PECS - Picture Exchange Communication System
- Augmentative/alternative systems that allow children and adults with autism and other communication difficulties to initiate communication
- No research available for children with DS and autism
- TEACH - The treatment and education of autistic and related communication handicapped children
- Develop a structure around the child's skills, interests and needs
- Organising the physical environment
- Developing schedules and work systems
- Making expectations clear and explicit
- Using visual materials

Practical resources


Resources

- TECERES, http://www.teceres.org/
- PECS resources, http://www.teceres.org/
- Literacy resources, http://www.teceres.org/

References

Have high expectations – beliefs matter

- We all have the potential to learn and develop across the life span from birth to old age
- Brains are not fixed at birth – the way the brain develops is influenced by input and activity from birth
- The important input is social – interaction with others
- In the family, school, work and wider community
- As we grow and learn we change at the biological, psychological and social levels
- Learning always involves brain change
- New skills increase self-esteem and confidence – they also increase social participation

Individuals with Down syndrome

- What matters for individuals with Down syndrome? How do we help them achieve their potential?
- Their development is influenced by the same things – family, education and wider community opportunities
- We can all make a difference but what do we focus on – what should be our priorities?
- I have told you about what I have learned wearing my professional hat as a psychologist supporting children, families and educators since 1970
- Now I want to tell you what my daughter Roberta with Down syndrome has taught me over the past 43 years.

Roberta's life so far

- Born in September 1969
- Into institutional care at 5 weeks – 'subnormality' hospital
- I met her at 9 months of age
- Fostered at 16 months
- Adopted at 10 years
- Left home at age 22
- Partner at 23

Not a 'high flier' – late to walk and talk

- Standing at 22 months
- Walking with truck - 32 months
- Finally walked unaided at 4.6yrs
- First intelligible words at 5 yrs
- Born before right to go to school – law changed in 1971
- Went to an ESNS (educationally subnormal severe) school
- Day care – not education
- Segregation – on the bus
- Low expectations

Teenage years with family

- (Event and details about teenage years with family)
Teenage years – my worries? Mental age?
- Still limited language
- Not fully continent at night until 13 years
- Not reading or counting
- Some skills at 'preschool' level
- At 17 not able to write name legibly or tie laces
- Still needed help with personal care
- I saw only deficits, delays
- I worried about the future

Roberta taught me to forget mental age and think chronological age at all times
- Roberta hit puberty, wanted to wear her jeans to school, sit with the boys in the bus, knew the pop groups watched the soaps – age appropriate interests, needs, behaviour but with limited language and less cognitive ability
- At 22 she fell in love and had a wonderful relationship for 5 years – still same emotions, needs and behaviour – she needs a bit more support, to live like you and I.
- A person with Down syndrome goes through life based on age – just like everyone else
- School at 5 years, puberty in early teens, out of school at 17 – the milestones are the same

Early 20's – getting a life!

Roberta showed me the importance of expectations and beliefs
- Roberta did not join the 'real world' until she was 22 when she moved to supported living
- Staff treated her like a young woman of 22 - who just happened to have Down syndrome but who had a right to an ordinary life – and she met Andrew and got a life!
- Staff attitudes and having a partner changed her self esteem and self identity dramatically – and her skills - more progress from age 20-30 than in previous 15 years.
- With Andrew she had social independence – could plan her own life – go out without staff or family
- We understand who we are and our place in the world by the way we are treated.

Roberta and Mark – current partner

Roberta taught me not to underestimate understanding
- The biggest difficulty that most children and adults with Down syndrome face – on a daily basis - is not being understood because they cannot put into words all they know and want to say – imagine how that feels
- Since Roberta reached adulthood she has constantly surprised us with her understanding and competence
- The way she has managed her life and relationships
- The way she has coped in emergencies – Mark has been in hospital as an emergency admission twice – the only person who could keep him calm and get him to let the doctors help was Roberta. She even had procedures first to show him it was OK and sat with him for many days (she probably has an IQ of 30-40??)
What has helped Roberta to succeed?
- Social competence and confidence – an extrovert
- The ability to learn the social rules and behave in socially appropriate ways in different settings such as at home, in school, in church, in a cafe or on the bus – this requires the ability to control one’s emotions, impulses, desires and behaviour
- The ability to make friends and maintain relationships – this requires the ability to understand other people’s behaviour and feelings and react appropriately
- Social competence determines the quality of life of any person – and is not predicted by mental ability
- It is learned through social experience

What else would have helped her?
- Better spoken language
- Some literacy and numeracy skills – better education
- Full inclusion in school and community as a child
- We have made much progress on these issues since Roberta was a child
- Research has given us a much greater understanding of the effects of Down syndrome on development
- Allowing us to develop more effective early intervention and teaching methods
- Attitudes to disability have changed

Quality of life – the vision
- A right to independence, dignity and choice – an ordinary life
- Same needs as all children – the need to feel loved and valued – at home, at school and in the community
- Leading to a sense of security, self-esteem and confidence – a secure base from which to explore and learn
- A secure and loving family, brothers and sisters
- A stimulating and quality school environment
- Friends and a sense of belonging in the world of childhood in their communities – participation, inclusion
- Not isolation and exclusion as is still all too common

The priorities?
- Think ‘person first’ – see the child/person not the disability
- Think chronological not mental age
- Think self-esteem and self identity – subtle expectations and feedback from everyone around
- Think social competence – it is learned through experience so requires social immersion/inclusion
- Think behaviour control – it is learned and begins at home
- Think communication – develop speech and language
- Think inclusion in education – and the value of literacy
- Remember the social strengths – build on these as all human development is social

Back to the big picture
- We all need to fight for the rights of our children to be fully included in the world of childhood
- We all need to enable adults with Down syndrome to be adult – independence, choice, work, partners – this last step is often hard for parents and depends on good services being available
- We all need to work to help them to be fully included in the social world, to have friends, take part in sports and leisure activities
- This is all starts with what we offer in early years and schools
- We all need to fight discrimination and prejudice in schools, communities and in wider society

Resources – DSE series of books and videos
- Both in DSE Development and Education series
- A series on Adult Issues is also available – edited by Roy Brown – and with an international team of authors
- All provide reviews of available research and guidance on evidence based practice.
- Available now by mail order from DSE see www.dseinternational.org
- Electronic versions and some translations available