Down Syndrome Education Conferences

Educators 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
Breakout sessions offer age appropriate guidance which will help you understand how students with Down syndrome develop and learn. Latest research findings indicating effective ways to help students with Down syndrome will be shared. Additionally, the presenters will share how you can use this research evidence to develop practical methods and activities to promote appropriate social and academic development in the home and educational settings.

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<td>Keynote: The learning profile of children with Down syndrome, implications of research for delivering effective education</td>
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<td>9:15 AM - 10:00 AM</td>
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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.

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.
DOWN SYNDROME SEMINARS

All sessions are 8:30 AM-11:30 AM
Down Syndrome Guild Conference Center
5960 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 ways to adapt 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:

[Image of seminar details]
CONNECT WITH THE PUJOLS FAMILY FOUNDATION

The Pujols Family Foundation proudly serves individuals with Down syndrome through extraordinary programs & services in St. Louis, Nashville, Southern California and Kansas City.

Please contact the Pujols Family Foundation to sign your child with Down syndrome up to participate in future programs & for up to date information follow us on social media.

In fact, get our your smartphone and connect with the Pujols Family Foundation right now!

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Down Syndrome Education International

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

Keep in touch with our work

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

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 early learning 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

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

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 very little about causes of speech-motor issues
  - Not just a motor issue
  - Planning component
  - Verbal short-term memory component

Looking in more detail at weaker areas - working memory

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

Baddeley's 2006 Working Memory Model

Central Executive

Verbal Short-term Memory

Visual Short-term Memory

Visual-Spatial Scratchpad

Episodic Buffer

Phonological Loop
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)

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

Executive functions are key being studied

• Working Memory – Hold information in mind for purposes of completing/sticking with an activity. Shift – Move freely from one situation to another, solve problems flexibly. Inhibition – Control impulses and behaviour at the right time/context. Emotional Control – Modulates emotional responses appropriately to situation.
• Plan/Organise – Anticipates future events/consequences.
• Lasnfranchi et al (2010) – adolescents with Down syndrome showed impairments relative to their MA on planning, inhibition, shift and working memory. Lee et al (2013) also report EF impairments and continue to study. EF. Working memory and shift improved with WM training (Bennett et al 2013) – very preliminary finding
• 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’

- 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
  - Sport 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 effects learning to talk and it effects processing spoken language and instruction.

If we plan interventions to
  - to focus on teaching spoken language
  - support all learning visually – especially with print
  - to improve and compensate for working memory

Can we make a difference?

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

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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.

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Language and literacy - inclusion study

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

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/295/.

The evidence for a specific phenotype or profile

- See Deborah J. Fidler (Colorado State University) and colleagues for a recent review of the evidence.

And free access articles - preschool, primary and teenage profile papers:
- Down Syndrome Research and Practice 9 (3) Special section on the specific profile for professionals at http://www.down-syndrome.org/research-practice/.

Relevant research evidence is growing

- Whole journal issues devoted to Down syndrome – important review papers in 2007.
- Important recent review papers and chapters on cognition (Silverman), language (Fidler et al., Roberts et al., Abdurubo et al., education (Fidler & Nadler), reading (Grosen et al., Buckley, Snowling et al.), social development (Ivancic et al., Ceula & Wishart).
- Gathercole & Alloway articles and books on working memory for teachers.

References – speech, language and memory

- J.E. Roberts, R.S. Chapman, & S.F. Warren (Eds), Communication and language intervention series: Speech and language development and intervention in Down syndrome and fragile X syndrome (pp. 233-254).

References – cognition and education

- Importance of full inclusion in changing the profile
Developing literacy skills

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 to 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 (Messer, Kucirkova in press)
1. Book reading

- Appropriate for language level
- Age appropriate – may be more difficult for older children

Supported 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

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  play
football  play
you  want

Sight words – teaching activities

- Word walls
- Character tubs
- 'Words I know' & 'Words I am learning'
- Physical games
  - Words on a ball
  - Flashcards around the room
  - Flashcards on the floor
- Write/trace word – sand, paint, pencils
- Pair's 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

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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 program 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/palindrome game, rhyme oddity, rhyme production
  - Works with pictures/objects/word cards
- Phonemes
  - Discriminating initial/end sounds:
    - Matching and sorting games
    - Ask child to match pictures or objects based on starting or ending with the same sound
    - Visual scenarios: ask child to find objects in a picture that start/end with a certain sound
    - Play tap (something beginning/end ing with)
    - Listen to spoken word pairs: do they start/end with the same sound or not?

I-Spy with picture support (film clip)

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? 'b-a-t'
    - Use pictures for support (cat, dog, hen... child points to correct one) but move on to listening only as child succeeds with pictures
  - I-spy with a few objects e.g. I spy with my little eye a 'p-a-er'
  - Segmenting
    - Use phonemes the child knows
    - Use a toy to do 'sound-talk': child does the sound talking - e.g. TA says, "Can you say 'cat' in sound-talk?"; child says, "c-a-t"
    - Phoneme frames: ask the child to sound out a word (e.g. dog) and put a cirriculum into the frame each time a sound is said.

Oral blending (film clip)

Film clip - segmenting
4. Phonics and phonological awareness

- Linking letters and sounds for reading
  - Repeat the 'sound talk' and phoneme 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; slice 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 (e.g. dog); 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

- Utilize 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
  - Expansive 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

Matching sentences to pictures

Comprehension support during reading
Comprehension activity

Materials for showing understanding and for retelling a story

The Jolly Postman
had a letter for the Bears.
He had tea.
Goldilocks sent the letter.

Sentences arranged by Matthew, age 8

Copyright © 2012 Dawn Sykes/Sez Ezeller International

Wreck of the Zanzibar – story board

Learn to refer back to text to find the answer

Where is the train going?
The train is going up the hill.

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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

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Ordering words to form a sentence (film clip)
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 phonics 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
  - Motivating
  - 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. Glicker.
- 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 you know 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
- Don’t introduce too many new targets at once

9. General guidance

- Practice and repetition
- Monitor and record achievements and progress
- Promote strategies for independent literacy with appropriate support
- Introduce new material and activities
- Home-school link
- Continue literacy teaching throughout school

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 (Burgoine 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

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 review
- 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

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

Resources – some software ideas

Clicker 6 software – UK and USA
http://www.cricksoft.com/uk/products/tools/clicker/home_a.10

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

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

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

Further information about RLI:
- DSE web site: http://dsunet/YlCsl1
- Scientific paper reporting RCT: http://dsunet/OXRO62
- Online events: http://dsunet/3wYXql
- New RLI blog: http://dsunet/ZMylZMI
- RLI email group: http://dsunet/RAhrlp

Handbook
- From UK store: http://dsunet/YRGLpa
- From US store: http://dsunet/XpYTCu

The RLI handbook
- Instructions for how to deliver each component, ideas for teaching activities and adaptations to suit individual abilities
- Practical information on delivering intervention, record keeping and collaboration
- Resources for assessments, teaching, planning and record keeping
- Videos illustrating each component and activities for teaching, including samples of children with different starting levels, strengths and weaknesses
- Background information on development and evaluation
- http://www.dseinternational.org/en- glish/resources/dspc/specifics/ for more information on the intervention

See and Learn - early intervention materials
- Visual supports for learning
- Language and learning from first sounds to words
- Number counting chart
- Further information
  • https://rli.com
  • Blog.rlicom
  • Dsepale

References to RLI and blending study
- See http://www.dseinternational.org/ english/resources/dspc/specifics/ for RLI training and support. 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.

Practical guides and resources
- Oelwein, 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 – literacy and Down syndrome
Developing speech and language skills – school years

Overview
Activities to support the development of spoken language skills:

1. Teaching vocabulary
2. Teaching grammar
3. An example of a targeted language intervention programme
4. Improving speech clarity – phonology and fluency
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

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
- 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

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 (800 word core vocabulary based on US research (CDI))
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

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 adolescence 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)

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

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>2-3 mins</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>5 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>5 mins</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 imageable
    - Not necessarily completely new
    - Looked at both % known and % use ratings
    - Related to themes

- Each theme targets range of word types (nouns, verbs, adjectives, prepositions)
- Words mostly taught in isolation but sometimes in pairs (e.g. on & in; tall & short)

- Work on base form but room to extend e.g. verb tenses
  - chew, chewing, chewed
Example from classwork

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

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

Introducing new vocabulary

Language Strand

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

Vocabulary game
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 word
   - 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

4. Speech development

Particular area of difficulty
- High incidence of hearing loss - important to monitor - prompt, effective treatment
- Phonological (speech sound) difficulties
- Verbal short term memory difficulties
- Poor auditory processing
- Differences in anatomy and physiology
- Oral motor skills

Speech difficulties limit language development and should be targeted for all children
4. Speech intervention

- Listening practice – sounds/words
- Discrimination – sounds/words/sentences
- Production practice – sounds/words/sentences
- Auditory bombardment
- Sorting by initial/final sounds in words
- Letters and sounds – phonics
- Focused articulation practice

Note overlap with teaching reading

Speech intervention

Focused articulation practice – Dyspraxia programme
- Listen and repeat single sounds (b)
- Listen and repeat c-v – (ba, boo, bee)
- Listen and repeat single sounds in repetition (b-b-b-b-b)
- Listen and alternate two single sounds (p-b, p-b)
- Listen and repeat words with target sound at the beginning
- Alternation of two words with contrast (pea- tea)
- Listen and repeat two syllable words
- Clusters

Film clip – speech – age 10

Summary (speech) targeting the profile

Improve articulation and phonology
- Encourage control over oral motor skills
- Build up sound discrimination and production skills
- Practise single speech sounds
- Keep a record of speech sound skills
- Practise whole word and sentence production
- Use signs and reading activities to support speech work

- Consider Dodd et al. Core vocabulary approach – working with parents and targeting useful vocabulary
Fluency and prosody – not much research

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

Interventions - fluency
- Younger children
  - Identify what you are doing that supports fluency – keep a diary of times the child is fluent and times speech is less fluent
  - Identify any patterns (e.g. time of day, setting)
  - Reduce communication and environmental demands
- Older children
  - Bigger focus of therapy (e.g. Inline school, clubs, friends)
  - Improving general communication skills
  - Slow down rate of speech for many
  - Relaxation, breathing and posture
  - Speech practice through reading, conversation and picture description, singing

5. 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 responsiveness to child’s speech attempts
5. Signing may reduce child’s spoken word attempts – use of voice/sounds/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

Capitalise 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

Summary (memory) - 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
Resources – practical books
- Kumler, L. (2008) Helping children communicate better (ages 6-14)
  Woodbine House
  Syndrome: A guide for parents and teachers. Woodbine House, Maryland
- Buckley, S. (2001) Speech and language development - an overview
  Children with Down Syndrome (5-11)
- Burgoyne, K., Duff, F., Clarke, P., Smith, G., Buckley, S., Snowling, M., &
  Hulme, C. (2012). A reading and language intervention for children
  with Down syndrome: Teaching manual. Down Syndrome Education
  International, Cambridge, UK – with DVD
  http://store.dseu.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.dseu.org/see-and-learn
- New See and Learn kits in 2014 for speech and language
  – in kit form and as apps, software programs
- Early interactive reading books by Joan Green
  E.g. Action!, 'What happened and why?', 'Pigs in space',
  'Who's on first', 'How do I feel?'
  http://www.greenhousepub.com/

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
  http://store.dseu.org/products/reading-language-
  intervention-down-syndrome-teachers-handbook

See and Learn – early intervention materials
- Visual supports for learning
- Language and reading from first
  words to sentences
- Speech from sounds to words
- Named coming shortly
  http://store.dseu.org/products/see-and-learn
- Further information
  info@downsyndromeeu.com
  http://www.dseu.org
  @SueTheink
Developing number and memory skills - school years

A range of skills
Research and implications
Number, counting and calculating
Money and time
Improving memory with supports & memory games

Understanding the number system
- Many children with Down syndrome enjoy numbers but most find them difficult
- There is very little research to draw on
- Early counting and cardinality at MA level (Nye
- Few adults achieve calculating to 100 at present
- Language, working memory and knowledge of number facts influence number development in all children
- Effect of cognitive profile?
  - language and verbal STM weak compared with non-verbal skills
  - working memory

Reading, language and number skills

Children with Down syndrome (aged 6-14 years at end of study)
- Reading comprehension (KORB)
- Vocabulary comprehension (DPSV)
- Number
- Grammar comprehension (TROG)

Range of skills 11-18 yrs, teenage study data
- More than ¼ of young people count to 20,
- About half to 50
- Around 1/3rd read, write, say numbers to 100
- Almost all add amounts up to 10
- More than ¼ of young people subtract numbers to 10
- Some add, subtract, multiply, divide for bigger numbers
  - helped by written sums, apparatus and calculator
- The majority of young people know:
  - days of the week,
  - months of year,
  - tell the time by the hour (half tell by quarter hour)

What can make a difference?
- All studies show that students respond well to good teaching
- Higher attainments by teenagers in mainstream education
- Quality and quantity of education affects learning in both mainstream and special schools
- Italian case studies show higher attainments in teenagers than in group studies
- Suggest our expectations should be higher (E. Monari-Martinez)

Maths tree
Italian teenager working with fractions
Italian teenagers learn algebra - Martinez

Range of examples growing

- Australian teenagers doing percentages with calculators
- (Rhonda Faragher Barbara Clarke – chapters on number and maths book on education for pupils with Down syndrome next year)
- Norway – simple statistics – counting numbers of cars of different colours then plotting a histogram
- Italy – algebra and problem solving with 15 teenagers with Down syndrome published

Teaching students with Down syndrome

- Make full use of visual, practical teaching methods
- Relate to interests, use skills meaningfully in daily life
- Teach language for number – vocabulary (in Dyslex number books)
- Discriminate and say number words – this is a challenge for many children due to speech issues
- Learning the number word list (count sequence) is a challenge – use number line for visual support
- More practice at each stage of learning
- Language- research shows gains if the key word is last ‘The ball is red’, ‘Look, balls, there are two’ (Ramsar et al)

Teach vocabulary and basic concepts

Shape and colour words
Circle/square/triangle
- Build with shape bricks, talk about shapes and features
- Size words, big, little
- Order words, first, last, next, before, after
- Comparison words – same, more, different, less
- Big, bigger, biggest – comparatives more difficult
- Pattern and order

Red, blue, yellow
Play matching and sorting games

A guide to steps in counting and calculating

Counting principles
- 1:1 correspondence
- Stable order
- Cardinality
- Order irrelevance
- Conservation of number
- Addition ‘count-all’
- Subtraction ‘counting-on’
- Subtraction 1-10
- Recall number bonds to 10

Place value for tens
- Count to 100 (say, read, write)
- Place value to 100
- Add & subtract more than 10
- Money – coin values
- Odd and even numbers
- Add & subtract within 100
- Multiplication, division, fractions
- Partitioning 2 & 3 digit numbers
- Target – numbers to 100 for daily life
- But many teenagers use money and count in daily life without this

Need to master counting principles

- 1:1 correspondence
- Order irrelevance
- Stable order
- Conservation of number
- Cardinality
- Takes time (5-7 years TD child)
Number is difficult – basics essential

- Learn to say count words
- Learn to use them to count – 1:1 correspondence
- Learn last count word tells you ‘How Many?’
- Link numbers with quantity – children can share items and know same or different before link with counting
- Understand quantity or succession – each next number is one more
- Equivalence – learn same size sets must have same number of objects
- Understanding quantity – can give correct number from larger set – ‘Give me x’ task is the test
- Move from ‘count all’ to ‘count on’ in addition
- Understand subtraction is inverse of addition
- Until a child has mastered these concepts for 1-9 cannot move on to place value, numbers above 10 – takes several years

Activities to teach counting and number

- Use visual support of number line to learn number words in stable order
- Start with learning to say 1-5 but to understand numbers 1-2, then 1,2,3,4,5
- Numbers 1,2,3 subitizable (known without counting)
- As children begin to understand numbers = quantity they are ‘1-knowers’, ‘2-knowers’, ‘3-knowers’ then ‘counting principle knowers’ in ‘give x’ task (Samecka)
- Play lots of games with objects making sets of 1 and 2, then 1,2,3 and so on – compare ‘same’, ‘more’
- Play linear board games (no line 1-5, dice 1,2) (Ramani & Siegler 2009).

Activities to teach number basics

- Play correspondence games with toys/objects to practice one-to-one correspondence
- Play linear board games (no line 1-5, dice 1,2)
- Play ‘give me’ games and end counting games with ‘How many?’
- Teach cardinality
- Play games adding a block, taking away a block to introduce the concepts of adding and subtracting and they are inverse relationship
- Introduce Numicon – visual-spatial representation of number. Powerful for teaching ‘each next number is one more’, relative sizes of whole numbers, adding.....
- Does not teach counting

Extra visual supports for learning number words

- Match, select and name
  - Numerals
  - Numicon shapes
  - Number words

Visually support learning number sequences

<table>
<thead>
<tr>
<th>Line</th>
<th>1 2 3 4 5 6 7 8 9 10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Square</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
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<tr>
<td></td>
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<td>123456789</td>
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<td>12345678910</td>
</tr>
</tbody>
</table>

- Practice different parts of the count sequence
- Rote count from other numbers than 1

Visually support development of cardinality

- With numerals, Numicon shapes, images, objects

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Support memory with number cards

Visually support learning about relative sizes 1
- Nesting dolls/pots/cups etc
- Numicon shapes, rods
- With Stern structural arithmetic materials

Numbers up to 100
- Counting up to 100 with 100 line, square, number cards
- Practice counting in ‘tens’ – understanding position in square, with equipment, tens cards, games to add 10

Similar sounding & similar looking numbers
- Lots of practice with ‘teens’, and ‘tys’
  Discriminating, matching, sorting, saying, reading.
  Writing down, matching to images (shapes, rods, Cuisenaire)
  Lotto games
  e.g. 17, 70, seventeen, seventy

Support addition for a ‘count-all’ strategy

Teach addition with other strategies
- Visually support counting-on with a numeral
  
  7

- With Numicon, spinner

- Make ‘one more’
Number bonds — learn visual imagery to support subtraction, taking away
- 'Taking away', 'Counting-back', 'difference' (counting forward)
- using a number line
- 'Chopping-off' using Numicon
- Recall of number facts, doubles
- Number sentence/stories

Place value — tens and units
- Stem dual board
- For units and tens
(Wave 3 resources cards)

Wider maths curriculum

Multiplication, division,
- Check odd and even numbers
- Repeated addition with images, apparatus and worksheets
- Meaningful practical tasks with equipment

Revision, practice

Money
- Match, select and name coins
- Play games with coin picture cards — snap, lotto,
- Play shops
- Practice adding coin values — with extra visual supports such as dots and Numicon shapes
- Use coins and notes — lots of practice
- Know costs of high interest items — activities, possessions
Time

- Relate times and clock reading to events in the day
- Learn to tell the time
- Wear a watch
- Count in 5's
- Know about a digital clock, analogue clock, 24 hour clock
- Calendar or flip chart
days, weeks, months

Everyday activities

- Pages on books
- Finding out things from wall displays, practical displays
- In measurements
- And 'how many....? games
  - How many are there?
  - How many do we need?

Summary

- Number challenges most students with Down syndrome
- Students will need supports for measurement, arithmetic, mental calculations and problem solving
- Visual parts of the maths curriculum are more accessible
- For example, shape, geometry, fractions, algebra, diagrams, graphs
- Need for extra resources

Individual practical resources

- Extra resources – bag, box
- Number cards to 100 – 2 sets
- Number line – to 10, 20, 100
- 100 square
- Calculator
- Ruler
- Practical equipment

Developing memory skills - research

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 categorisation and rehearsal strategies

Activities to improve phonological loop function

- Listening games
- Sound discrimination
- Auditory bombardment
- Word discrimination
- Links with literacy, phonics, spelling
Activities to improve attention and increase processing abilities

- Sitting still
- Computer games
- Choosing games - objects, pictures, gestures/signs
- Following instructions, one to one, in a group, following teacher direction in whole class
- Waiting for turn
- Reading books with an adult
- Teaching new play/leisure skills

Activities to improve and support remembering

- Hiding games, Memory games
- Rehearsal training (apply e.g. spelling, numbers)
- Auditory rehearsal
- Grouping & organisation skills (sorting, oddity task, memory tasks in categories)
- Computer games – DSEI cog med trial
- Recalling activities, stories
- Delivering messages
- Lists (pictures, words) for self help and independence

Film clip – rehearsal strategy

Rehearsal training

Rehearsal strategies – numbers, number recognition for large numbers, spelling

Cogmed JM/RM – See www.cogmed.com

- JM = 75 games
- RM = 200 games
- Designed by psychologists and computer games designers
- Adaptive training on a trial by trial basis constantly adapting to each individual's WM capacity
**Working Memory and the Brain**

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

Training results in changes in the density of neural connections. O’Mahony, McNab & Varonec, Feb 2009.

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**Pilot**

5 Children with Down syndrome
Tavary, J., Manetto, C., Schloss, J. G., A.
Cogmed training completed at home.

1. PPVT (Peabody Picture Vocabulary Test)
2. 8 Subtests of the WMSA (Verbal & Visual STM/WM)
3. BRIEF parent version

Showed children could use the programme and supported a further study.

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**Main Study**

24 Children with Down syndrome
Tavary, J., Manetto, C., A., G.
Cogmed training completed at school.

1. RCT random assignment: 32 (10%)
2. WMSA (Wechsler Memory Scale - Revised)
3. BRIEF A parent version (extension)

21 children completed training (Group 1 ~ 10), Group 2 (N = 11). Improved on visual spatial short-term memory tasks. The improvement was sustained 4 months later.

See Bennett, S., Hulme, J., Burnley, S. (2013)

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**Summary**

- Cogmed training was feasible and improved short term visual memory for children with Down syndrome in our study.
- Cogmed training may be suitable for younger children with appropriate support – also depending on their existing memory skills.
- Children who completed Cogmed training had less problems on WM & SHIFT (BRIEF-P).
- Gains are sustained – children likely need more frequent practice. JM intervention programme less intensive than RM (25 activities v 200) – current case study of RM showing continuing gains.
- Planning a larger study in USA – to see if gains in verbal STM, language and academics.

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**Resources and references**

- Numicon teaching kits: http://www.numicon.co.uk
- 1st Steps with Numicon at Home is a starter kit for parents
- Numicon Firm Foundations kits – One-to-one and Class Kits
- See whole Numicon range at our online store
- Horstmeier, D. (Books 1 & 2) Teaching math to people with Down syndrome and other hands-on learners. Woodbine House
- Articles on number (Buckley et al.) and case studies – see http://www.down-syndrome.org/newsupdate/2005/

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**Additional resources**

- Numiconshark CD and other teaching materials - http://www.numicon.co.uk
- Range of software from Inclusive technology, http://www.inclusive.co.uk
- Time cooler Quality in Education Centre, Strathclyde University
- See and Learn Number – developing See and Learn kits and apps to teach first maths concepts (size, shape, colour, pattern) and first counting (i.e. adding and subtracting 1-9) – coming 2014
- Buckley, S., Bird, G. Memory Development for individuals with Down syndrome. Down Syndrome Issues and Information
- http://www.educationalsupport.org.uk/information/memory/overview/
- Bird, G. & Buckley, S. Number skills for children with Down syndrome 5-11, 11-16 years. Down Syndrome Issues and Information
- http://www.down-syndrome.org/information/number/childhood/childhood

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**Reading and references**

- Bird, G. & Buckley, S. Number skills for children with Down syndrome 5-11, 11-16 years. Down Syndrome Issues and Information
- http://www.down-syndrome.org/information/number/childhood/
- http://www.down-syndrome.org/information/number/childhood/
- University of York website about memory – for parents and teachers
- http://www.york.ac.uk/isc/wm/dementia/teachers100
Strategies for accessing the curriculum

- Setting educational targets
- Adaptations to teaching and assessment approaches
- Principles for differentiation
- Additional resources to support learning

What is inclusion in education?

- Belonging to your school and community
- Being of equal value
- With recognition of the same needs, rights
- Removal of barriers - to enable participation and expression
- Learning and developing within this context
- Using the framework of the curriculum

What are the educational targets?

- To become socially competent – learn the social rules, manage emotions and make friends
- To develop language and literacy skills
- To develop math skills
- To learn about the world around – science, history, geography
- To develop physical abilities
- To engage in art, drama and music
- To find strengths and develop self-esteem and self-confidence
- The same as all children – so what needs to change?

Some key principles

- **Literacy and math** – the targets are the same, progress requires learning the same building blocks - no short cuts
- Smaller steps – more explicit teaching and modelling
- More time to learn – more repetition and practice
- Generalisation needs to be taught

- **Science, geography, history** – most topics can easily be simplified and often one topic not dependent on knowing another. Adds to general knowledge – link to the child’s world, the world of the family – what siblings may be learning or doing and to the community and culture

- Take care IEPs do not limit student

What is differentiation?

The process which allows students to access a common curriculum and includes any modification made by a teacher or assistant to respond to student diversity in the classroom

- **Content**, e.g. adapting learning objectives
- **Process/Task**, e.g. adapting the teacher/student activities and resources, allowing for extra practice
- **Products/Outcomes**, e.g. adapting assessment methods and expectations according to the learning objectives

- **Learning Environment**, e.g. adapting the physical and social environment (Tomlinson 1999)
**Range of skills and abilities**

- Students with Down syndrome differ widely in their understanding, abilities and skills
- General principles are useful but teachers must plan for the individual
- Students with Down syndrome may not always be the most ‘delayed’ in the class
- It is not helpful to think of them as ‘like younger children’
- They will be delayed in conceptual understanding but need access to age appropriate content
- The following principles will optimise learning for most students

**Adaptations to teaching**

- Teachers need to understand the learning profile
- Learn about the individual – through records and interaction/teaching
- Appreciate the need for supporting listening skills and how they can do this through visual supports
- Appreciate the need for language teaching – vocabulary, grammar, conversation, communication
- The need for activities and resources that engage the individual
- Understand the need for development of the individual across the curriculum and within the school community

**Learn about the individual – Head, teachers, teaching assistants**

- Through discussion with parents
- From written records and assessments
- Statement from statutory assessment
- From people in partnership services who know the pupil well – hearing, vision, OT, Down syndrome specialist
- Through interaction with the pupil, supported by use of visual books, conversation diary – learn about interests, family
- Learn about attention, motivation, behaviour and strategies that help the pupil

**Pupil passport**

- A guide developed by the child
- Shared between relevant staff and students
- Includes important and useful information about the child:
  - Medical information
  - Family and friends
  - Strength areas
  - Areas they find more difficult
  - Information on personal interests, motivation and favourite topics
  - Behaviour management/strategies

**Adaptations to assessment, records**

- Evidence of participation – take photos, create a portfolio, make personal reports, include pupil’s views
- Two records?
  - One for assessment file
  - One for student and parents to enjoy, share
- Assessments for vocabulary learning and new knowledge
  - Not relying on expressive language
  - Using visual supports/special equipment
- Assessments, celebration of new practical skills
  - Use of photos, videos, personal books,
  - share new skills and experiences with others (practice)

**Engaging visually, supporting listening, enhancing understanding**

- Written lesson (scheme) objectives – adapt as necessary
- Visual and gestural augmentation – pictures, objects, ICT, photos
- Differentiate – visual supports for presentation, activities, response/review
- Words and sentences – for the pupil to read, write, show, or stick
- Clear visual and written plan for pupil – visual timetable
- Rewards and praise
Individualised learning

Too much individualised teaching in a 1:1 setting can:
- reduce exposure to age appropriate models of behaviour/language and opportunities for pupil to pupil interaction
- lead to social exclusion, feeling different
- make it difficult for staff - teacher and/or assistant roles
- may be too demanding for pupil and assistant

Pace, keeping busy

- Too slow a pace may lead to:
  boredom, frustration, fatigue, lack of motivation, behaviour problems
- Improve pace by:
  Reminding pupil about next activity
  Changing activities regularly
  Have something ready if you finish earlier that expected
  Use the pupil's cues to know when to change
  Allow the pupil to make choices
  Allow breaks and reward success with special activities

Understanding the day - Picture time table (4-5 years)

Active participation – things to do, words to match, flaps to lift, age 4-5 years

Resources for literacy – learning words, ordering sentences (year 3, 7-8 years)

Drawings to hold attention while listening during teacher presentation (6 years)

- The assistant, seated with the child, draws pictures as the teacher reads the story
- This enables the child to listen and behave well during this part of the lesson
Interactive literacy activity (year 1, 5-6 years) - words to arrange and stick in

Interactive literacy activity - a picture to open

Differentiation to key vocabulary and simple sentences (age 6-7 years). The story of the town and the country mouse.

Storyboard 'writing frame' for supporting literacy (age 11). Macbeth - this method can be used from age 5 (who? where? what? why? etc) with pictures and sentences.

Inclusion – learning in classroom

Participation (year 6, age 10) with help from peers. (Connor has Down syndrome and a hemiplegia)
Participating in a writing activity with help from assistant, peer and resources

Inclusion in American history lesson

Resources for participation - French

Resources for revision – Glue materials into the child’s record books (age 5-6, health and safety lesson)

Inclusion in math

Records - maths and science (year 3, 8 years)
Geography – the local area – home to school

Making a record of activities

Differentiation, age 8

Class project about water.
Key questions and answers; a word web.
Vocabulary and sentences explain:
- rain, cloud, river, lake,
- pond, reservoir, people
- and water use, transport,
- contaminated water

Contents

What is water?
Where do we find water?
Who needs water?

Inclusion in drama
Inclusion in science

Inclusion in music

Learning and literacy

Case study – age 6 years 2 months

- Background:
  - Hearing – fluctuating conductive hearing loss
  - Vision – visual impairment within the range of partial sight
  - Speech and language – Understanding 3-4 key word phrases, using 2-3 key word phrases
  - Reading – good awareness of print and books, able to read approximately 4 words
  - O.T. And PT – has delayed fine and gross motor skills
  - Other – some challenging behaviours
Case study - age 6 years 2 months

- Recommendations
  - Positioning and access to resources to support hearing and vision e.g. Laptop, print size, dome magnifier, front of class
  - Daily practice of reading (whole words), early phonics skills and handwriting
  - Use of visual aids - visual timetable, pre-written word cards, second copy of teaching materials, additional pictures, access to appropriate computer programmes: Numicon
  - Record books supported by written sentences and pictures/photos
  - Activities to target IEP targets e.g. Topic vocabulary, counting 1-10, speech clarity
  - Activities broken down into small steps with rewards built in throughout all classes

More specific teenage goals?

Independence and an adult life

- A home of my own
- Self-care: shopping, laundry, cooking
- Work
- Friends, partners, marriage - sexuality
- Leisure activities
- Travel, money

Education for life

Educational implications? An education for life

- Making choices - like the other students - based on interests and aptitudes with work in mind
- A balanced and individual curriculum

Why is inclusion important?

Education is to teach children - evidence suggests that both academic and language outcomes are better when children with Down syndrome are fully included in regular education.

Education is to fit children for life - social learning from and with peers is as important as learning from teachers - for all children.

People with Down syndrome have the right to be full members of your communities - and this must include school communities.

We will only change attitudes to disability when we stop excluding and allow all children to learn and grow together.

Inclusion is not difficult

- We have been supporting full inclusion in education since 1988
- Success requires the belief that inclusion is the right of the child - attitudes are critical
- When teachers believe inclusion is right, problems are positively solved
- When teachers do not embrace inclusion - children go back to excluding special education settings
- Does not need to cost more - requires new thinking and new ways of using existing staff and resources
- All schools should be inclusive - valuing individual differences and teaching to individual needs for all pupils

Resources

- See Down Syndrome Issues and Information books at Downseed Online shop
- Downseed DVD about Primary Inclusion - online shop
- Inclusion and how to do it, Meeting SEN in Primary Classrooms (2004) Sue Briggs, Published by David Fulton
Supporting full social inclusion

- I want to draw attention to three aspects of social inclusion
- Building the child's self-esteem and confidence
- Supporting friendships
- Encouraging age-appropriate social behaviour and avoiding behaviour difficulties
- Full social inclusion is sometimes overlooked - and the child always seen as 'different'
- Some research shows that the more time a child is engaged in one to one activities outside the classroom the less they are socially included by the other children

Factors for developing self esteem and confidence

- Acceptance of one's identity
- Development of competence, success
- Understanding of one's own talents and gifts
- Feeling that one is loved and loveable
- Learning needs to be fun
- Being given responsibilities
- Being given choices

Supporting friendships

- Reciprocal – shared interest and activities
- Acceptance, loyalty, commitment, genuineness, common interests, intimacy
- Friends - share experiences - do things together - take care of each other - like one another
- Need for a range of friendships
- Need friends with a disability – for identity and adjustment in teenage years

Breaking down barriers to social inclusion

- Limited spoken language for sharing lives and making friends
- Use communication supports
  - make books – my family, weekend trip, holiday, news - using photos, pictures, postcards so that child can share his/her life with other students despite limited language
  - Conversation diary – events and activities to be shared as well as help to improve spoken language

Conversation diary. 5 year old example, for sharing at school – suits any age and all types of schools
Breaking down barriers to social inclusion

Limited social and play skills for age
- Need to structure shared activities with mainstream peers at some play or break times
- Ensure that the activity is one the child with a disability can do competently and enjoy. Other children must play the game at that level to ensure the child is able to participate
- Modelling and scaffolding – by adults for the other children – adult role models matter
- Lunch time clubs

Prevention of behaviour difficulties
- A key to promoting positive social behaviour is taking a proactive approach
- Important that parents establish sense of control from early and that home and school work together on any behavioural issues
- Actively teach positive social behaviours, self-regulation and ways to express emotions
- Use positive language
- Reward positive behaviours throughout the day

Buddy system – ‘my lining up friend’

Preparation - going on holiday book

Set realistic and achievable targets
- Give warning and preparation time for transitions, changes and demands
- Give children small jobs and responsibilities
- Use visual time tables and reminders to promote co-operation and independence
- Provide ways of making choices and having some control
**Prevention**

- Provide positive peer role models and reward imitation of positive behaviours
- Keep child busy to avoid boredom
- Ensure appropriate communication systems are in place
- Many difficulties may be prevented by a change in routine and a change in adult behaviour at home or at school as the behaviours are predictable

**Classroom preventative practices**

- Adequate materials
- Balanced schedule — group size etc
- Defined play centres
- Structured transitions
- Individualise instructions for children who need support
- Design activities that are engaging to children
- Provide clear directions
- Teach small number of rules

**Social emotional teaching strategies**

- Teach children to identify and express emotions

  
  Teach and support:
  - self regulation — learning to wait, supported by boundaries, by friends, by visual supports
  - collaboration with peers
  - friendship skills
  - strategies for anger and disappointment
  - social problem solving

**Developing social skills**

- Increase awareness of emotional responses and eye contact
- Teach sharing, turn taking, waiting, offering, receiving
- Teach communication skills — 'move', 'help', 'finish', 'yes', 'no', 'go away please', 'I'm busy'
- Encourage social interest in others — watch others and talk about what that they might be thinking and feeling — include reference to age appropriate behaviour

**Changing difficult behaviours**

- ADULT BEHAVIOUR MUST CHANGE IF YOU WANT CHILD BEHAVIOUR TO CHANGE.
- This may need a high level of support especially when problems have existed for a long time.
- Everyone concerned with the child must agree to act in a consistent manner or behaviour will not change.
- Time spent on planning how to change behaviour is essential and must involve everyone in contact with child reaching a consensus and working together.
Identifying behaviours to change

Behaviours that may...
- Be harmful to the individual, others or property
- Impede the individual or others' enjoyment of an activity
- Interfere with learning or ability to carry out a task
- Draw negative attention to the child
- May be damaging to relationships with others, e.g. family members, friends

Developing a behaviour plan

PREPARATION
- Observation – identify ABCs
- Summarise results
- List possible functions
- Devise plans for decreasing unwanted behaviours and teaching new behaviours
- Data collection/record-making
- Review of data
- RECOGNISE ADULT BEHAVIOUR MUST CHANGE

The ABC of behaviour

Objective, accurate observations essential

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Understanding the observations

- Data analysis – compare and analyse information
- What patterns are there?
- What are the conditions when the behaviour is most likely to occur?
- What are the conditions when the behaviour is least likely to occur?
- What are the probable consequences that maintain the behaviour?
- What are the functions of the behaviour?
- Gain attention? Avoid activity? Seek excitement? Other?
Can we understand the functions?

- Sensing things — during play at meal times?
- Hitting or poking others
- Pulling hair
- Spraying
- Eating and drinking — difficult mealtimes?
- Difficult bedtimes
- Running off
- Refusal behaviours — avoidance, lying down on floor
- Grinding teeth — other noises
- Sweating?
- ?

Summarise results, devise a plan

- List possible functions — for avoidance, attention, control, to reduce anxiety?
- Device plans for:
  - Decreasing unwanted behaviours
  - Teach new replacement/alternative behaviours (skills)
  - What rewards can be used for positive behaviours and new skills?
  - What behaviours can be prevented?
  - Decide how to respond to unwanted behaviours
  - Decide how to monitor progress
  - Identify training needs and resources

General strategies for responding to difficult behaviours

- Calm, consistent responses and consequences
- Always consider consequences from child’s perspective
- Provide opportunities for positive attention and praise as soon as possible
- Personal reward systems — need to do motivator assessment
- Social stories
- Clear visual communication systems
- Calm, uncluttered, quiet environments

Example: social story

Example — to stop negative behaviour to parent at going home time

Photographs and sentences show the following story:
- I get my bag and coat
- I say goodbye to my friends
- I walk across the playground
- I see my Mum
- I say ‘Hello Mum’
- We smile
- We walk home together

The story is read several times just before leaving school.

Strategies for responding to difficult behaviours

- Attention should be withdrawn both verbally and non-verbally (‘emotional ignoring’)
- Social interaction should be resumed, without reference to the inappropriate behaviour after 30 seconds (or so)
- Discussion of bad behaviour should be avoided completely — discussion gives room for negotiation, social interaction, displays of emotion are rewarding
How to monitor progress

- Have frequencies of targeted behaviours changed?
- Have frequencies of new behaviours being taught increased?
- How do you share information between the team, especially parents?
- Review data every two weeks, for some behaviours every week, share and discuss experiences
- When to change the plan
- Review your rewards
- Check on consistency

Examples: coming in from play

- Intervention: for coming in after playtime
  - "Hello" to do = hold door, give message, hold bell
  - Come in before bell
  - Hold hand before bell raps to prevent running
  - Reward for coming in when bell goes = child chooses
  - Do not reinforce refusal = lock away, do not show emotion, do not allow child to run off and do other things
  - Check out classroom situation precipitating factors

Examples: laying down – when moving about building

- Stop reinforcing behaviour – pause, no eye contact, no discussion
- After a while (20 secs) ask child to come with you nicely – use gesture
- Repeat as above if the child responds negatively
- Praise warmly when child is on her feet and moving – wait till she is, before engaging
- Use prevention strategies – from the ABC record you will know when this behaviour is likely to occur

Examples: Magic pots and sparkles – for praising in class

- Useful for children who do not have assistants
- Child makes a magic pot for the teacher
- Teacher notices good behaviour in class and ask child to place an item in his/her magic pot
- At a suitable time for the teacher, the teacher and child empty the pot and talk about the items - what the teacher noticed, to praise the child again and reinforce positive behaviours
- Sparkles are reward cards that anyone can give to anyone to acknowledge positive behaviour – whole class/school system

Recommended reading and resources

- Right to know CCI 2014 – Down Syndrome Society of South Australia
- Woodbine House – excellent series by Terri Gouwenber
- Teaching Children with Down Syndrome about Their Bodies, Boundaries, and Sexuality. A Guide for Parents and Professionals
- The Girls’ Guide to Growing Up
- The Boys’ Guide to Growing Up
**What vision should underpin our work?**

- 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 4:6 yrs
- 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**

- Not a ‘high flier’ – late to walk and talk
- Standing at 22 months
- Walking with truck – 32 months
- Finally walked unaided at 4:6 yrs
- 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 – 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 wider society

Resources – Dsi series of books and videos

- Both in Dsi 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

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