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.

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

Setting the scene for effective education

What do we know about the effects of Down syndrome on development?

First – the big picture across all areas of development

Second – a closer look at the areas of specific weakness

Do we know any of the reasons for this profile?

What are the implications of what we do know for intervention strategies?

If we apply these strategies – can we improve the areas of weakness and change the profile?

Applies in special and mainstream classrooms – and to many other children

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

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**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)**

<table>
<thead>
<tr>
<th>Weaknesses</th>
<th>Strengths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Motor Skills</td>
<td>Social understanding, empathy &amp; social skills</td>
</tr>
<tr>
<td>Social understanding, empathy &amp; social skills</td>
<td>Self help and daily living skills</td>
</tr>
<tr>
<td>Hearing and Vision</td>
<td>Visual short-term memory</td>
</tr>
<tr>
<td>Speech and Language</td>
<td>Information processing</td>
</tr>
<tr>
<td>Verbal short-term memory</td>
<td>Learning from listening difficult</td>
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<tr>
<td>Number</td>
<td>Non-Verbal Mental Age</td>
</tr>
<tr>
<td>Visual short-term memory</td>
<td>Reading</td>
</tr>
<tr>
<td>Non-Verbal Mental Age</td>
<td>Strength</td>
</tr>
</tbody>
</table>

**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 (Pennanen, 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 nothing of early speech discrimination in children with Down syndrome.
- Speech difficulties will delay language development.
- We know very little about causes of speech-motor issues.
  - Not just a motor issue.
  - Planning component.
  - Verbal short-term memory component.

Looking in more detail at weaker areas — working memory

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

Baddeley’s 2006 Working Memory Model

- Central Executive
  - Verbal short-term memory
  - Phonological loop
  - Episodic buffer
  - Visual short-term memory
  - Visuo-spatial scratchpad
Working memory is important for all children

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


Verbal short term memory & language

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

Working memory in children with Down syndrome

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

Why this profile?

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

Effects of poor verbal short term memory function

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


Executive functions now being studied

• Working Memory – Hold information in mind for purpose of completing/sticking with an activity. Shift – Move freely from one situation to another, solve problems flexibly. Inhibition – Control impulses and behaviour at correct time/context. Emotional Control – Modulates emotional responses appropriately to situation.
• Plan/Organise – Anticipates future events/consequences.
• Lanfranchi et al (2010) – adolescents with Down syndrome showed impairments relative to their MA on planning, inhibition, shift and working memory. Lee, Fidler et al. (2011) 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

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

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

In summary
• Children with Down syndrome are visual learners
• They find learning from listening particularly difficult
• This effects learning to talk and it effects processing spoken language and instruction
If we plan interventions to
  – to focus on teaching spoken language
  – to support all learning visually – especially with print
  – to improve and compensate for working memory
Can we make a difference?
Our data for teenagers taught in this way from preschool years suggests we can

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

- Very significant gains in literacy (mean gain 3.3 yrs) 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.

Vineyard Adaptive behaviour Scale - age scores

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 reviews 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 free at:

Related 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, Abbeduto et al., education (Fidler & Nadel), reading (Groen et al., Buckley, Snowling et al.), social development (Iarocci et al, Cebula & Wishart).
- Gathercole & Alloway articles and books on working memory for teachers.

References – speech, language and memory


References – cognition and education


Importance of full inclusion in changing the profile

Developing literacy skills - teenagers

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 word can support articulation and phonology so improve speech intelligibility.
- These benefits are true also for non-readers (i.e. supported reading activities)

Overview

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

1. Book reading

- Experience with a range of reading books
- Books with words – not picture books
- Personal books
  - Personal books are about the students life and interests as well as targeting the school curriculum.
  - These books should be:
    - Written as if the child has written it themselves
    - Written at an appropriate language level for the child
    - Created together with the child to build understanding

Supported reading

Topic work
1. Book reading

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

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 2.6-3.6 years of age
- Older children/adolescence – same principles, adapt resources and activities

Example of matching board

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
- Pairs games (pelmanism)
- Pictures

2. Sight words – which words?

- Beginning readers:
  - Family names
  - Character names
  - Personal and motivating
  - Words child understands
- 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
3. Letter sound knowledge

- Important for phonics
- Individual sounds, digraphs (oo, ay, ee, etc.) and clusters (sl, sn, dr, cl etc)
- Structured sequential progression
  - Map on to phonics progression e.g. Jolly Phonics
- 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

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/pelmanism 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 scenes: ask child to find objects in a picture that start/end with a certain sound
      - Play i-spy (something beginning/ending 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’: TA does the sound talking – What word is the toy saying? ‘c-a-t’
    - I-spy with a few objects e.g. TA says, I spy with my little eye a ‘p-e-n’
  - Segmenting
    - Use phonemes the child knows
    - Use a toy to do ‘sound-talk’: child does the sound talking – TA says, “Can you say ‘cat’ in sound-talk?” child says, ‘c-a-t’
    - Phoneme frames: ask the child to sound out a word (e.g. dog) and put a coin/counter into the frame each time a sound is said

Oral blending (film clip)

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 1/2 extra) and ask them to spell out ‘cat’
  - Spread out the magnetic letters that spell a word, ask child to say each letter; slide the letters gradually closer to one another; the child says the letters faster together, until they blend them into the whole word
  - Give them flashcards with words and ask them to sound them out (d-o-g), then put them together to form the word (dog)
  - Model sounding out whenever a child gets stuck on reading a word in their reading books
5. Support comprehension

- Utilise visual strengths
  - mental imagery techniques e.g. teaching children/young adults to picture stories in their minds when answering questions
  - using picture cues to visualise segmented sentences, full sentences, short stories.
  - Using picture cues to discuss feelings, make predictions, explain causal events, etc.
  - Write questions and provide answer choices
- Support vocabulary and grammar
  - Difficult/new words and/or contexts, word tense etc.
  - Direct teaching
  - Provide other examples, model and demonstrate, etc.
  - Formulating sentences with flashcards

5. Support comprehension

- Retelling/summarising/sequencing activities
- Predicting/inferencing
  - use of modelling and scaffolding
- Questioning
  - answering questions and formulating questions
  - Natural discussion
  - Expressive demands – support e.g. give choices, picture selection tasks, written questions, etc.
- Strategies
  - Look-back
  - Using context (including pictures)
  - Link to world knowledge and personal experience
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

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

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

8. ICT

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

- Make reading fun
  - Use a variety of activities and/or presentations
  - Be enthusiastic!
  - Start sessions with something 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

- 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

Concluding comments

- All teenagers 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

- Down Syndrome Issues and Information books – Reading and Writing 11-16 and Reading Overview available online
- Books designed for slower readers and English as additional language readers
- Make books for curriculum, interests and holidays
- Oelwein, P. Teaching Reading to children with Down syndrome. Woodbine – new edition with CD of work sheets
- Make use of IT and web – learning e mail and text use

References

- Moni & Jobling – Latch-On literacy for young adults http://www.down-syndrome.org/reports/290/
Language instruction for teenagers with Down syndrome – and RLI

Professor Sue Buckley OBE
Director of Research
Down Syndrome Education International

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 – speech work needed
- Vocabulary paces 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

In teenage years – speech and language work

- Vocabulary development and interventions
- Grammar development and interventions
- Speech development and interventions
- Fluency issues
- Supporting the social use of language and communication

Vocabulary Learning

- DSE checklists 1, 2, 3, curriculum interests and motivating words to teach
- Liaising with parents/home
- Make it visual
- Use target words in sentences as well
- Promote vocabulary organisation
- Include social/emotional vocabulary – mental state verbs (thinking, knowing, remembering, wishing)
- Personal dictionary
- Word webs/closed set activities

Combining words – grammar intervention

- Modelling
- Imitation and expansion
- Use of signs
- Reading games
- Pictures/props
- Personal books
- Pacing boards
- Carrier phrases
- Repetition and practice

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 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

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

Further in depth information – and support

- Evaluated in UK 5-10 year olds
- Scientific report published in Journal of Child Psychology and Psychiatry: http://dsuri.net/OXRO0Z (free access)
- Successful pilot in Texas Public School District 2012-13 school year
- Further information on RLI web site: http://dsuri.net/RYCs1

Our findings

- On most measures intervention group progressed faster
- Some small gains, some larger – 4 were statistically significant (unlikely due to chance): letter knowledge, word reading, phoneme blending, expressive vocabulary
  - These reflect directly taught skills – and these gains did not yet transfer to gains in spelling, non word reading or standardized language measures. (Maybe not a surprise given the demands of the reading tasks and the extent of language difficulties for children with Down syndrome.)
  - The waiting control group progressed faster when they moved to the intervention – and showed similar gains to the intervention group

Individual differences in progress

- Wide variation in progress made on intervention – some children made rapid progress, other slower progress and some very little progress
- What influenced progress? - age, receptive language and no. of sessions
- Younger children tended to make more progress – those starting at 5 and 6 years
- Children with better receptive language tended to make more progress
- Bt not all 5 and 6 year olds went fast and some older children did, some children with more delayed receptive language progressed with reading
- Children receiving at least 80% of the intervention sessions made more progress
  - The only advice we can give is to try it – well planned and adapted to the individual child.
- Other (unmeasured) factors may also contribute

Feedback from teaching assistants

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

• Supported evidence from standardized tests

Many people have commented how much Fix-up has progressed and that they can now understand him.

Guidance

• Suitable for children with Down syndrome aged from 5 to 11 years (max reading of 8 years)

Can be delivered by teaching assistants and should preferably be delivered as part of school education

• Recommended where Resources and commitment to deliver RLI consistently for at least 20 weeks

Starting the program

• Identify 2+ key staff to deliver intervention

• Team approach: class teacher, special educator, reading specialist, teaching assistants, speech and language therapist

• Spend 3-4 weeks familiarising yourselves with program and organising how you will deliver it in your school

Starting the program

• Organizing delivery

• Quiet place in school – consistency

• Single session or two shorter sessions

• Time of day

• Time for planning, preparation and delivery

• Preparing to start

• Assessments of existing skills

• Find and grade books

• Gather resources – visual supports, phonics resources, etc

• Photocopy resources – planning and record forms etc

• Share teaching targets and get help with preparing

Session structure

<table>
<thead>
<tr>
<th>Task</th>
<th>Component</th>
<th>Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reading</td>
<td>Long format reading</td>
<td>20 min</td>
</tr>
<tr>
<td></td>
<td>Instructional level book reading</td>
<td>5 min</td>
</tr>
<tr>
<td></td>
<td>Sight word reading</td>
<td>2.5 min</td>
</tr>
<tr>
<td></td>
<td>Letters, sounds and phonology</td>
<td>5 min</td>
</tr>
<tr>
<td></td>
<td>New instructional level book</td>
<td>5 min</td>
</tr>
<tr>
<td>Language</td>
<td>Introducing new words</td>
<td>5 min</td>
</tr>
<tr>
<td></td>
<td>Reading the meaning of new words</td>
<td>5 min</td>
</tr>
<tr>
<td></td>
<td>Using new words in connected speech</td>
<td>5 min</td>
</tr>
<tr>
<td></td>
<td>Using new words in written language</td>
<td>5 min</td>
</tr>
</tbody>
</table>

Individualizing the program

• Wide range of abilities, interests and motivations

• Important that the program is pitched at the right level for the child

• Assessments taken before starting determine right starting level

• Ongoing assessment and records of progress

• Suggestions for ways to adapt/extend the program

• Be confident and use your knowledge of the child

• Examples of children with different skills and abilities on the DVD
Reading Strand

- Assessment for learning
- Strand begins with a series of assessments
  - Knowledge of letters and sounds (phonemes)
  - Word-level knowledge
  - Text-level knowledge
  - Reading text
- Essential for pitching the program at the right level for the individual child
- All assessment materials and instructions included

Running Record

- Also known as miscue analysis
- Essential component of instructional book reading
- Formative assessment
  - Tracks reading and accuracy levels
  - Helps determine teaching (when to move on to the next book/level)
  - Identify child’s reading strengths and weaknesses
- Taken before starting program and in every teaching session
- Instructions provided

Book reading (components 1, 2 and 5)

- Easy level book (1)
  - >84% accuracy
- Instructional level book (2)
  - 90-94% accuracy
  - Running record taken
- New book at instructional level (5)
  - Shared/guided reading
  - Becomes next book for assessment

Books

- Experience of a range of real reading books
  - Topics
  - Publishers
  - Motivating and interesting to child
- Levels from beginning readers to RA of 8 years
  - Starting point determined by assessment
  - Read 3-4 books at each level (consolidation)
  - Running Record determines when to move to next level (progression)
- Finely graded - Hatcher grading scheme (Hatcher, 2000)
  - Information provided for you to grade books that are available in school
  - Book list from research project (widely available books) is also provided

Sight word learning (component 3)

- Words child can read by sight
  - Strength in children with Down syndrome
  - Many high frequency words in English are not readily decodable
- Which words?
  - Beginning readers: personal words, characters, motivating words
  - High frequency words (Letters & Sounds, DCSEP): first 100, next 200
  - Topic words from school
  - Tricky words from reading books

Sight word teaching

- Word walls, word hunts, flashcards, physical games......
- Including practice of ‘known’ words and new learning
- In isolation and in context
- Pace dependent on child
Letters, sounds and phonology (component 4)

- May be difficult but essential for independent reading
- Starting point determined by assessments
- Follows a clear structure and progression (Letters & Sounds, DCSF)
- Levels of PA: syllables, rhymes, phonemes
- Listening to sounds and linking letters and sounds
- Different skills: learning letter sounds, alliteration, sound isolation, blending, segmenting

Example teaching activity:

**I-Spy with picture support (film clip)**

**Language Strand**

- Introducing and reinforcing meaning of new words
- Using the new word in expressive language (spoken and written)
- Increase children’s breadth of vocabulary (understand and use more words)
- Increase children’s depth of vocabulary (understand more about words they know)
- Highly interactive
  - Components can be tailored to individual abilities
- Visual

**Choosing vocabulary to teach**

- Which words?
  - Related to themes
  - Useful
  - Motivating and meaningful to the child
  - Where possible imageable
  - Not necessarily completely new
- How to identify words?
  - Classwork/topic work
  - DSEI checklists
  - Consultation with parents/SLT
  - Reading books
Language Strand

- Each theme should target a 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

<table>
<thead>
<tr>
<th>Week</th>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
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<td>Cereal</td>
<td>Cheese</td>
<td>USA</td>
<td>East</td>
</tr>
<tr>
<td>2</td>
<td>Bread</td>
<td>Ice</td>
<td>Not</td>
<td>Friend</td>
<td>London</td>
</tr>
</tbody>
</table>

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

Vocabulary game

- (2) Reinforce word meaning: Increases the depth of the child's understanding of new vocabulary by discussing word meanings in different contexts
- Activities are game-based e.g.:
  - 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

Expressive language film clip
Language Strand

• Work on expressive language: Encourage 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
  • Guided by child’s language level; aim to increase utterance length or complexity
    • Encourage/model/extend appropriate grammar
    • Scaffolded by TA

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

Language Strand resources

• 4 weeks (2 themes) of scripted language work are provided
• Suggestions for teaching activities
• Guidance on choosing words to teach
• Ideas for finding visual supports for use in teaching
• Link with curriculum – use DSE vocabulary checklists, curriculum topics, speech and language therapy targets

The handbook

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

The handbook

• Available from our UK and US offices
  • UK: http://dsuri.net/YRGrLp | US: http://dsuri.net/XpY1Cu
Developing number and memory skills
A range of skills
Research and implications
Number, counting and calculating
Money and time
Improving memory with supports and memory games

Research
- Many children and young people with Down syndrome enjoy numbers
- 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

Range of skills 11-18 yrs, teenage study data
- More than ¾ 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 ¾ 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?
We know the quality of teaching is important
- All studies show that students respond well to tuition
- 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
Implications from research for teaching students with Down syndrome

- Make full use of visual, practical teaching methods
- Relate to interests, use skills meaningfully
- Teach language – vocabulary (in Dsii number book)
- Discriminate and say number words
  Learn number sequences
  Recall number facts
  Place value
  More practice at each stage of learning
  Young people can learn how to use money without fully understanding the number basis

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 they link with counting
- Understand ordinality or succession – each next number is one more
- Equinumerosity - learn same size sets must have same number of objects
- Understand cardinality – 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 and 1,2,3,4,5
- Numbers 1,2,3 subitisable (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) (Raman & Siegler 2009).

A guide to steps in number, counting and calculating

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

1 2 3 4 5 6 7 8 9 10
• Practice counting in 'tens' – with equipment, tens cards
• Practice different parts of the sequence
• Practice counting up to 100 with 100 line, 100 square and number cards

Visual supports – words, amounts, relative size
• Number cards
• Number words
• Numicon
• Stern

Similar sounding & similar looking numbers
• Lots of practice with 'teens', and 'ty's'
  Discriminating, matching, sorting, saying, reading, writing down, matching to images (shapes, rods, Cuisenaire)
  Lotto games
  e.g. 17, seventeen, seventy

Support addition for a 'count-all' strategy
Joe is drawing circles then counting them all

Teach addition with other strategies
• Visually support counting-on with a numeral
• Visually support counting-on with a number line
• Make 'one more'
• Learn about doubles (shapes)
• Addition facts

Number bonds – learn visual imagery to support Strategies for subtraction, taking away
• New vocabulary and ideas
• 'Taking away'
• 'Counting-back' or 'difference' (counting forward) - for subtraction using a number line
• 'Chopping-off' using Numicon activities, e.g. 7 - 3 = 4
• Recall of number facts
• Number sentences/stories
Place value – tens and units

Wave 3 resources provide place value chart and partitioning cards.

Equal balance equals – a ‘Year 1 kit ’ Numicon activity

- Big idea: Equivalence
- Teaches equals sign, bigger than, smaller than signs
- Language – greater than, smaller than, larger, greater, smaller, less, more, compare

Number sentences

Linking with interests: adding ‘one more’; doubles with dice

Multiplication, division, fractions

- Odd and even numbers
- Repeated addition with images, apparatus, worksheets (Wave 3)
- Multiplication squares, games, facts
- Use a calculator
- Understand word problems, convert to numbers
- Suitable workbooks (D. Horstmeier Books 1 & 2)
- Stern workbooks

Practice
Learn coin values
Money – encourage use and independence
• Match, select and name coins
• Play games with coin picture cards – snap, lotto,
• Practice adding coin values – with extra visual supports
• Have pocket money
• Use coins and notes
• Know costs of high interest items
• Use payment cards (lunch system)
• Practice working out costs in ICT projects – plan to buy things for a purpose, online
• Use a money planner/record book (Joseph article)

Time
• Relate times and clock reading to events in the day
• Learn to tell the time (Time cracker resource, ICT)
• Wear a watch
• Count in 5’s
• Know about a digital clock, analogue clock, 24 hour clock
• Calendar or flip chart – days, weeks, months

Developing skills in everyday situations
• Page numbers
• ‘Finding out’ activities, how many items/money?
• Link to familiar situations, hobbies
• Time measures (how long until…, when will…?)
• Planning – calendar, planner
• Measurements – weighing, scales, dials, digital, analogue
• Recording – notebook and pen
• Calculator

Strategies for an individual, 13 years old
• Use maths ‘stories’ for addition and subtraction problems e.g. include favourite film and TV character or classmates names to keep pupil focused
• Use menus and ‘shops’ to encourage addition of money amounts
• When remembering clock times prompt by pointing upwards for ‘o clock’ and downwards for ‘half past’
• Vary activities throughout the lesson and give choices of activity to maintain concentration
• Use mini whiteboards to sketch visual aids during the lesson

Joseph’s book keeping
• Keep track of spending – bus, cafe, snooker, cinema, presents
• Take out book and pen
  – Starting Money:
  – Money spent:
  – Money left over:
  – Money spent + money left over = Starting money
• Keep receipts
• Do the sums with help
• Compare costs, discuss
• Managing his own bank accounts at 18

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
• 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 (spelling, phonics, sound and word discrimination games)
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 remembering lists of numbers of items

- Memory games
- Rehearsal training (pictures, numbers, words and sentences, spellings)
- Auditory rehearsal
- Grouping or organisation skills (sorting, oddity task, memory tasks in categories)
- Computer games – cogmed trial

Rehearsal training

Developing and supporting working memory

- Recalling activities, stories
- Delivering messages
- Lists (pictures, words) for a series of activities to promote self help and independence
- Pictures to prompt and support
- Using a daily and weekly calendar to plan for the future, and to discuss the past
- Practising checking skills and increasing independence – watch, clock, calendar, timetable, personal belongings, packing school bag, phone,

Cogmed JM/RM – See www.cogmed.com

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

5 Children with Down syndrome
Cogmed training completed at home.

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

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

**Main Study**

24 Children with Down syndrome
21 Mainstream, 3 SEN. 7-12 years.
Cogmed training completed at school.

RCT random assignment (G1 N= 12, G2 N=12)

1. KBIT 2 (Kaufman Brief Intelligence Test)
2. 4 Subtests of the AWMA (Verbal and Visual STM/WM)
3. BRIEF P parent version (preschooler)

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

**Summary**

- Cogmed training was feasible and improved short term visual memory for children with Down syndrome in our study (7-12 year olds).
- Children who completed Cogmed training had less problems on WM & SHIFT (BRIEF-P executive function measure).
- Gains are sustained – children likely need more frequent practise JM intervention programme less intensive than RM (75 activities v 200) – current case study of RM showing continuing gains.

**Future directions**

- University of Surrey Neuroscience Team collecting baseline AWMA data on a MA matched typical group with us:
  1) To enable memory profile comparisons of different participant groups using AWMA.
  2) To enable us to see how much memory training has boosted raw & standard scores of children with DS to those seen in TD children of the same MA without intervention.
- Bid submitted for larger RCT of Cogmed RM with teenagers with Down syndrome (CA: 15-20) with Holmes– outcomes language and speech.
- Bid submitted for multi site RCT of an adapted version of Cogmed RM for children with Down syndrome in UK and US (CA: 10-17) with Kronenberger – outcomes reading comprehension, mathematical reasoning, attention, EF.
- Both unsuccessful – still looking!!

**Resources**

- Numicon products available at Downsed online shop http://www.downsed.org/
- Firm foundation kit or Closing the gap, Numicon kit 1, Numicon kit 2, conversion to kit 1, conversion to kit 2
- Time cracker Quality in Education Centre, Strathclyde University www.strath.ac.uk/qie
- Numbershark - http://www.parentscanteach.co.uk/
- Teaching math to People with Down Syndrome. Book 2, by DeAnna Horstmeier, Woodbine House 2008
- Inclusive technology, http://www.inclusive.co.uk

**Reading and references**

- Buckley, S., Bird, G. Memory Development for individuals with Down syndrome. Down Syndrome Issues and Information
  http://www.downsyndrome.org/information/memory/overview/
- University of York website about memory – for parents and teachers
  http://www.york.ac.uk/res/wmi/indexteachers.htm
- Bird, G & Buckley, S. Number skills for teenagers with Down syndrome 11-16 years
  http://www.down-syndrome.org/information/number/adolescent
- Buckley, S. Teaching numeracy, Down Syndrome Research and Practice Update 12,1
- Brickstoke, S., Hulme, C. & Nye.I. Number and arithmetic skills in children with Down syndrome.
  http://www.down-syndrome.org/reviews/2070/
Teenage track
Strategies for designing and 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
As relevant to teenage years

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

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' especially in teenage years
- 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

Engaging visually, supporting listening, enhancing understanding
- Written lesson (scheme) objectives – adapt as necessary
- Visual and gestural augmentation – pictures, objects, ICT, photo's
- 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

Inclusion – learning in classroom

Learn about the individual – Head, SENCo, teachers, assistants
- Through discussion with parents
- From written records and assessments
- Statement from statutory assessment
- From people in partnership services who know the student well – hearing, vision, OT, Physio, 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 student
Pupil passport

- A guide developed with the student
- 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 student’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)

Curriculum attainments and target setting – as part of the school system, planning with parents

- Learning new concepts, ideas, knowledge (vocabulary) and new experiences, responsibilities
- Social development, behaviour, participation, friendships
- Independence, self help, personal care
- Literacy – reading, writing, spelling, handwriting, ICT
- Speech, language and communication
- Number and maths skills, measures, (money, time)
- Physical development – sports, dance, PE, movement/mobility, seating, posture
- Fine motor skills for self help, equipment, art and craft, drawing, writing
- Development through creative and expressive arts

Inclusion across the curriculum

Inclusion in science

Acquiring ICT skills
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 than expected
  - Use the pupil's cues to know when to finish or change
  - Allow the pupil to make choices
  - Allow breaks and reward success with special activities
Storyboard ‘writing frame’ for supporting literacy (age 11) Macbeth (who?, where? what? why?) with pictures and sentences

Inclusion in history

Differentiated worksheets

Inclusion in American history lesson

Making a record of activities

Inclusion in math
Participation (year 6, age 10) with help from peers. (Conor has Down syndrome and a hemiplegia)

Participating in a writing activity with help from assistant, peer and resources

Resources for participation- French

Health and safety – simple approach

Records - maths and science – simple approach

Resources

- See Down Syndrome Issues and Information books at DSE Online shop
- DSE DVD about Primary Inclusion - principles are the same
- Down Syndrome Association London see at http://www.downs-syndrome.org.uk/information/for-professionals/education.html
- CD Education Support for Schools
  Education for Secondary Schools
Adolescence track
Developing social, emotional and practical independence
Facilitating full social inclusion and friendships
Peer support – buddy systems, circles of friends
Personal care, health, sexuality and close relationships
The role of sports, leisure and community activities

Goals of adolescence?
• Preparing for adult life – leaving home
• Independence – in self care, travel, money, shopping, cooking
• Making educational choices for adult employment
• Developing own personalities, values, likes, dislikes
• Developing confidence, able to make decisions, manage emotions
• Dealing with body changes, attractiveness, body image
• Sexuality
• Friends, special friends, boyfriends, girlfriends
• Same or different??

Factors for developing self esteem and confidence – important for social inclusion
• 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

Self esteem and self image (McGuire et al)
• To regard oneself with pride and respect
• Majority of adults have high self esteem – attributed to families and carers promoting self esteem
• Importance of accepting - it is difficult to develop your talents and advocate for yourself if you cannot accept Down syndrome
• Need to keep discussion in teens (even if discussed in younger years) to develop a positive and realistic view
• Simple and honest statements, strength and weaknesses
• Developing a sense of competence – skills, break into steps, encourage interests, not too quick to take over, encourage person to accept mistakes as part of learning

Self awareness in young adults with Down syndrome (Glenn and Cunningham)
• 77 young people with Down syndrome, 17-24 years
• Interviews with young people and parents
• Developmental progression in that only those with higher mental ages were able to make comparisons (verbally)
• They made more downward than upward comparisons (this is good for mental health)
• Parents largely referred to lateral comparisons (family members)
• Aspirations were age appropriate

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
• Invite friends home
Friends, emotional well-being

Friendships need active planning and support
- Parents need to take initiative out of school
- BUDDY SYSTEMS
- CIRCLES OF FRIENDS – need to extend beyond school
- Personal, Social and Emotional (PSE) curriculum – an opportunity to discuss
- DRAMA, SPORT, LEISURE SKILLS will help – encourage a wide range of social activities
- Social skills and confidence are learned in social situations
- PARTICIPATION is the key

Statistics on friends DSE teenage survey

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 teenager can share his/her life with other young people despite limited language
- Conversation diary – events and activities to be shared as well as help to improve spoken language

Self-talk in adolescence (From D. McGuire)
- Helpful self-talk
  - To direct behaviour
  - To think out loud and to vent emotions
  - For entertainment
- When to worry
  - Changes in frequency and context
  - Dominated by self-disparagement and self-devaluation
  - If it becomes loud and threatening
  - If person becomes agitated
Do's and don'ts for self talk (From D. McGuire)

• Don't make person feel bad
• Don't try to eliminate
• Discuss self-talk – it is OK, but some people bothered by it
• Might be polite to self-talk in private
• Encourage appropriate places for self-talk
• Consider a private signal to remind the person if in public
• Explain the normalcy of self-talk to people who come into contact with the person

Developing emotional understanding

• Teach vocabulary for emotions – from simple to complex
  – E.g. Happy, sad, tired, hungry, angry, proud, scared, use pictures, observe others, use in role play/drama
• Use a graded programme for teaching social skills – 'Talk about' or 'About me', SEAL resources
• 'Right to Know about Friendships, Sexuality, Personal safety' DSSA

The Right to Know Continuum – Friendships 5 – 18 years www.downssa.asn.au

• About me
• About others
• Personal space
• Grooming – child – nose, face, personal hygiene, clothes, dry/clean pants, looking cool
• Feelings, self – e.g. happy, sad, angry, hurt, sick, tired
• Feelings, others – as above
• Feelings, self – more advanced vocabulary e.g. silly, frustration, teasing, scared, harassment, anxious
• Grooming – adolescent (key concepts as for child)
• Feelings others – more advanced vocabulary – as above
• Relationships

The Right to Know Continuum – Sexuality 5 – 18 years www.downssa.asn.au

• Body parts 1 & 2
• Puberty for girls – body changes male and female, menstruation, hygiene, hormones, understanding moods/feelings
• Puberty for boys – body changes male and female, wet dreams, hygiene, understanding hormones and moods/feelings
• More about puberty – body changes of the opposite sex, hygiene, masturbation
• Reproduction and Birth control (14+) – understanding sex, safe sex, STDs, contraception
• Sexual expression – self control of urges, appropriate sexual expression, understanding sexual feelings, understanding emotions

The Right to Know Continuum – Personal Safety 5 – 18 years www.downssa.asn.au

• Public and private – behaviour, places and body parts
• Interpersonal boundaries – hug, high 5, hello circle, ignoring unknown people, identifying circle names, appropriate greetings, greet or ignore
• Safety in the community – safe at home, school, staying close, safety houses, community, public toilets, to and from school
• Assertiveness training – public and private touching, keeping safe, assertiveness skills, keeping safe rules
• Abuse prevention strategies – body and face signs, body parts, early warning signs, touching, telling, helping hand, secrets

Sexuality, relationships

• Most do well
• Learn to manage physical changes
• Learn to manage behaviour
• Inappropriate behaviour rare
• Terri Couwenhoven books – great resource
• Last taboo?? Most parents over protective?
• Many adults with Down syndrome treated as perpetual children??
Benefits of partners?

- Social support – someone to do things with and may well increase independence in community
- Self-image and self confidence
- Someone to love
- Someone for whom you are special
- Prevents loneliness
- Share daily living activities
- Someone to take care of you in sickness and health
- Respecting the right to be adult and have the same social and emotional needs as everyone else

Need to work at practical independence

- Think age appropriate
- Have high expectations
- Skills to be learned
- Privacy in bathroom, shower
- Do not continue to do things because it is easier or quicker
- Independence in self care is good for self-esteem
- Our teenage surveys are positive – most can be independent in personal care by late teens

Practical independence: personal care

- Dressing/clothes
  - 85% choose new clothes
  - 70% find appropriate clothes
- Bathing
  - 90% use the bath
  - 80% dry self
  - 50% run own bath
  - 30% wash own hair
- Nails
  - 10% cut own nails
- Toilet use
  - 25% need some help in toilet
- Teeth and hair
  - 100% can clean teeth, brush hair
  - 50% actually do this

Practical independence – DSE survey

- At home
  - 85% had own bedroom
  - 65% keep it tidy
  - 90% put up posters
  - 15% help with chores
  - 35% safe to leave (short period)
  - 8% safe to leave (longer)
- Out and about
  - 30% go to shop alone
  - 80% receive pocket money
  - 45% cross road alone

Practical independence: meal times

- 95% eat and drink
- 30% cut up food
- 95% serve themselves
- 90% eat out in restaurant
- 100% get class of water
- 95% make squash
- 80% get glass of milk
- 50% make sandwich, tea
- 35% use can opener
- 25% use microwave
- 10% use oven/grill
- 80% lay/clear table
- 50% wash and dry crockery

Health eating – healthy lifestyle

- Encouraging a healthy lifestyle – diet, activity
- Joan Medlen – dietician with son with Down syndrome and autism has written a book and cooking resources
- The Down syndrome nutrition handbook: a guide to promoting healthy life styles 2006
- Excellent advice on health and nutrition – and materials
- http://www.downsyndromenutrition.com/phronesis/
- Joan also maintains Disability Solutions – much helpful material
- http://www.disabilitysolutions.org/
- Her nutrition handbook is available downsed shop
Sports, leisure and community activities

- Swimming
- Dancing
- Walking
- Ball games
- Any sport that young person enjoys
- Housework – laundry, shopping, cleaning
- Fitness activities – gym, aerobics, cross trainer
- Wii fit and sports
- Create social and inclusive opportunities

Leaving home

- Does anyone really grow up if they stay at home??
- The right to a place of my own
- Making my own decisions
- In control of my life
- My own choices
- Privacy, dignity
- The barriers??
- Moving in early twenties - an advantage

The vision

- In conclusion
- We need to think age appropriate, ordinary life
- Preparing for a home of one’s own, even if this is a bed-sitting room
- Own privacy – personal care skills matter
- Ability to care for own room and clothes
- Prepare meals – which are healthy
- Have friends and relationships
- Enjoy a social life and leisure activities

Recommended reading and resources

- Social development for individuals with Down syndrome – An overview. Sue Buckley, Gillian Bird, Ben Sacks (2002)
- Right to Know CD 2004 – Down Syndrome Society of South Australia
- SEAL resources: archive of photos http://nationalstrategies.standards.dcsf.gov.uk/node/89143?uc=force_us

Reading and resources

- Dsii Adult series of books on all adult living topics
Encouraging age appropriate behaviour and changing inappropriate behaviour

1. Encouraging age appropriate behaviour and avoiding ‘difficult’ behaviour
2. Strategies to change unwanted behaviours

Why does behaviour matter?

A person’s behaviour affects ...

- the way other people behave towards us
- happiness, opportunities and quality of life
- friendships and other relationships
- ability to learn and participate in the ‘mainstream’
- likelihood of finding gainful employment
- likelihood of living independently

In the drama group

Research into behavioural difficulties

1. Children with Down syndrome have similar levels of behaviour difficulties to typically developing children of same mental age
2. They have fewer difficult behaviours than others of same chronological age with similar level of learning difficulties (but not Down syndrome)
3. They will have more behaviour difficulties than same-age typically developing peers – mainly due to cognitive and speech and language delays. This matters for inclusion.

See details in Dsii Social Overview book on reference list for detailed review of the behaviour research studies

Research findings – some implications

- We need to teach new skills to help behaviour to move forward – the teenager may get ‘stuck’ developmentally
- Research shows that behaviour difficulties decrease with age and most teenagers and adults with Down syndrome have good social behaviour.
- However, while difficult behaviours last they are distressing at home and/or school
- Behaviours are learned and can be changed
- Behaviours are often different in different situations and with different individuals – a clear indication that they can change

At the gym
Prevention – at school

• Is the student having a good time? Liaise with home, consider emotional well-being
• Actively teach positive social behaviours, self-regulation and ways to express emotions – ‘insight’
• Use positive language
• Reward positive behaviours throughout the day
• Ensure positive relationships with key staff and students
• Change support assistant if negative relationship
• Do not provide too many different assistants

Prevention – home and school

• Set realistic and achievable targets
• Give warning and preparation time for transitions, changes and demands
• Give jobs and responsibilities
• Use visual time tables and reminders to promote co-operation and independence
• Provide ways of making choices and having some control
• Provide ways for student to communicate about worries, changes, preferences

Prevention – home and school

• Provide positive peer role models and reward imitation of positive behaviours
• Keep student busy to avoid boredom
• Ensure appropriate communication systems are in place (see Talking Mats)
• Ensure speech and language is being taught
• 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

Peer role models

Classroom preventative practices

• Adequate materials
• Balanced schedule – group size etc
• Structured transitions
• Individualise instructions for children who need support
• Design activities that are engaging to student
• Appropriate differentiation and inclusion
• Provide clear directions
• Teach small number of rules

Social emotional teaching strategies

• Teach teenagers 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
• Encourage social interest in others – watch others and talk about what they might be thinking and feeling – include reference to age appropriate behaviour

Developing social skills

• Teach vocabulary for emotions – from simple to complex
  – E.g. Happy, sad, tired, hungry, angry, proud, scared, use pictures, observe others, use in role play/drama
• Use a graded programme for teaching social skills – ‘Talk about’ or ‘About me’, SEAL resources
• ‘Right to Know about Friendships, Sexuality, Personal safety’ DSSA

Dealing with difficult behaviours

• Have high expectations – do not blame ‘Down syndrome’
• Children repeat ‘difficult’ or ‘challenging’, behaviours because they WORK for them – they get rewarded (attention, escape, avoidance, control)
• Not because they have Down syndrome
• Difficult behaviours are learned and can be unlearned
• Sometimes behaviours are the only way they can tell you something is wrong – poor/limited communication skills increase likelihood of difficult behaviours
• See Chapter by Emily Jones et al – ref at end of slides

Changing difficult behaviours

• ADULT BEHAVIOUR MUST CHANGE IF YOU WANT STUDENT’S BEHAVIOUR TO CHANGE
• This may need a high level of support especially when problems have existed for a long time.
• Everyone concerned with the student 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 the student reaching a consensus and working together.
• NB Understanding behavioural methods is important for teaching new skills not just for changing difficult behaviour – see also in Jones chapter

Developing a behaviour plan

PREPARATION
• Review history and recent events
• Observation – identify ABCs
• Summarise results
• List possible functions
• Devise plans for decreasing unwanted behaviours and teaching new behaviours
• Data collection/recording methods
• Review of data

The ABC of behaviour

conditioning bridge

| cue signal trigger stimulus | Behaviour | consequence reward result reinforcer |
Individual record - ABC

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Timetable style record

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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? (antecedents)
- 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?

Summarise results, devise a plan

- List possible functions – is something wrong?, has something changed? for avoidance?, attention?, control?, to reduce anxiety?
- Devise 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 student’s perspective
- Provide opportunities for positive attention and praise as soon as possible
- Personal reward systems – need to do motivator assessment
- Social stories – teach the positive
- Clear visual communication systems
- Calm, uncluttered, quiet environments

General 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 – 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 – individual, whole school reward system, both approaches?
- Check on consistency

Examples

- Touching other people’s things – pencil cases etc
  - Reminder about expectations for behaviour – positively phrased, prior to entering situation – similar to social story
  - Praise and rewards for student remembering
- Swearing
  - Teaching activities
  - Reminders, rewards, ABC - prevention, no longer ‘reward’
- Inappropriate physical contact
  - Teaching activities
  - Reminders, rewards
- Refusals

Examples: refusals to move – when moving about building

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

Behaviour matters long-term

- It is a person’s behaviour, whether it be socially appropriate or unacceptable, that is the single most important factor which determines the way in which they are regarded
- And how their personal relationships develop, how they are helped or rejected, where they live and ultimately, how happy they are and how good their quality of life becomes.
- Most people with Down syndrome do not have behaviour difficulties

Recommended reading and resources

- Social development for individuals with Down syndrome – An overview. Sue Buckley, Gillian Bird, Ben Sacks (2002)
- Down Syndrome online http://www.downsed.org/
- Right to Know CD 2004 – Down Syndrome Society of South Australia
- SEAL resources: archive of photos http://nationalstrategies.standards.dcsf.gov.uk/node/89143?uc=force_uj
- Talking Mats – communication supports see http://www.talkingmats.com/

Reading and resources