Westin Crown Center
Registration Fees: $75 per person/$125 for two attendees
Register online by January 15, 2014 at http://conference.kcdsg.org/

Speech/Language Pathologist Track
Friday, January 24, 2014
8:00 AM - 4:30 PM

Educator Track
Thursday, January 23, 2014
8:00 AM - 4:30 PM

Parent/Family Member Track
Saturday, January 25, 2014
8:00 AM - 4:30 PM

Parent Track
Ages 7-16

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
**Parent/Family Member Track**

Breakout sessions offer age appropriate guidance which will help you understand how a child with Down syndrome develops and learns. Latest research findings indicating effective ways to help children and teens 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.

<table>
<thead>
<tr>
<th>Time</th>
<th>Early Years Track (0-6 Years)</th>
<th>Childhood Track (7-16 Years)</th>
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<tbody>
<tr>
<td>7:30 AM - 8:00 AM</td>
<td>Registration&lt;br&gt;Continental Breakfast (included with registration fee)</td>
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<tr>
<td>8:00 AM - 9:00 AM</td>
<td>Keynote: What are the priorities for parents - the view from research and from personal experience as a parent</td>
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<tr>
<td>9:15 AM - 10:00 AM</td>
<td>Developing speech, language and communication at home</td>
<td>Supporting friendships, social development and managing behavior</td>
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<tr>
<td>10:15 AM - 11:15 AM</td>
<td>Ways to play and encourage motor, cognitive development and early numbers</td>
<td>Developing speech, language and communication at home</td>
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<td>11:30 AM – 12:30 PM</td>
<td>Sharing books and teaching early reading</td>
<td>Developing maths, time and money skills</td>
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<tr>
<td>12:30 PM - 1:30 PM</td>
<td>Lunch On-site (included with registration fee)</td>
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<tr>
<td>1:30PM - 2:30 PM</td>
<td>Keeping a balance-taking care of the needs of the whole family</td>
<td>Sharing books and supporting reading development at home</td>
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<td>2:45PM - 3:45 PM</td>
<td>Supporting social development, independence and Managing Behavior</td>
<td>Looking towards the future—planning for independence, relationships and a full adult life</td>
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<tr>
<td>4:00 PM - 4:30 PM</td>
<td>Closing remarks and Q&amp;A</td>
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Becky Baxter CertMRC SLT

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

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

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

Sue Buckley

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

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

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

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

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

Down Syndrome Specific Curriculum Supports
December 12, 2013 OR April 17, 2014
This educator led interactive seminar will help you better understand education support materials designed for learners with Down Syndrome. Curriculums which improve reading, literacy, math, handwriting and memory skills will be covered. We will explore how these programs can be applied to your existing curriculum. Attendees will:
- Identify Ds specific curriculum, programs and tools
- Discuss common core standards and how to apply
- Evaluate IEP goals and assignments
- Review unique learning profile of students with Ds
- Learn helpful instructional styles that promote success
- Identify ways to motivate and engage students in the classroom
- Evaluate what works and 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 Down Syndrome Guild of Greater Kansas City]
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.

Down Syndrome Education International

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

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/

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 would like to tell you what my daughter Roberta with Down syndrome has taught me over the past 43 years.
- And then what I have learned wearing my professional hat as a psychologist supporting children, families and educators since 1970.
Roberta's life so far
- Born in September 1969
- Into institutional care at 5 weeks - 'subnormality' hospital
- 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

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 of family.
- We understand who we are and our place in the world by the way we are treated.

Roberta and Mark - current partner

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

What have I learned from research?

- 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)

- **Hearing and Vision**
- **Speech and Language**
- **Verbal short-term memory**
- **Learning from listening difficult**
- **Number Weaknesses**
  - Non-Verbal Mental Age
  - Strengths

The specific developmental profile associated with Down syndrome

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

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 working memory difficulties
- Strengths in visual 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) delay
Working memory deficits will affect all learning

Baddeley's 2006 Working Memory Model

- **Central Executive**
- **Verbal short-term memory:** Phonological loop
- **Visual short-term memory:** Visuo-spatial scratchpad
- **Episodic buffer**

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
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

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

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What parents can do

• What you do at home makes a big difference
• Language is learned all day, every day – talk to your child, do some teaching – more input needed
• Reading progress will be influenced by your input – most competent readers taught at home
• Number progress will be influenced by your input
• What you do at home supports school and makes a difference – as it does for all children
• You create opportunities for social learning – lots of social experience important
• You create opportunities for motor development and sporting activities

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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

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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/

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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.

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.

Keys to success

- 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.

Education and intervention resources

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

Down Syndrome Education International DVDs - infant development, preschool speech and language, inclusion in education.

DSE vocabulary, speech and grammar checklists
- See http://store.dseenterprises.org/ for all the above items.

The evidence for a specific phenotype or profile

- See Deborah J. Fidler (Colorado State University) and colleagues for a recent review of the evidence.
- The Emerging Down Syndrome Behavioural Phenotype in Early Childhood. Infants and Young Children (2005) 16, 2, 86-103
- The Down syndrome behavioural phenotype: implications or practice and research in occupational therapy. Occupational Therapy in Health Care (2011) 25, 7-25

And free access articles - preschool, primary and teenage profile papers.
- Down Syndrome Research and Practice 9 (3) special section on the specific profile free at
down syndrome education international

discovering potential - transforming lives

Supporting social development, friendships and behaviour at home

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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
- Behavior management at home is a priority and a parent responsibility – for all children
- Behavior is learned and can be unlearned – there are no excuses

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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

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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

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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

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Conversation diary, 5 year old example, for sharing at school - suits any age and all types of schools

Copyright © Down Syndrome Education International

I played at Wacky Warehouse, met Charlie, Helen, Owen and Vienna
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 enjoys. 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

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 – as 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

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

Consider background factors

- Health
- Sleep – very important
- Hearing and vision – maintain aids and spectacles
- Upsets, unpleasant events – may not have the language to tell you
- Sudden changes in behaviour – always suspect an event
- Ongoing behaviour difficulties need addressing after possible reasons ruled out

Prevention

- 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
- Use reward systems - wisely
Preparation - going on holiday book

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
- Encourage social interest in others – watch others and talk about what that they might be thinking and feeling – include reference to age appropriate behaviour
- Remember to respect child’s chronological age – same social and emotional needs as others and understand more than you may think

Developing social skills

- Teach vocabulary for emotions – from simple to complex
  - E.g. Happy, sad, tired, hungry, angry, proud, scared, use pictures, observing others, in role play
- Use a graded programme for teaching social skills – “Talk about” or “About me”, SEAL resources
- “Right to know about Friendships, Sexuality, Personal safety”
- DISA
- Full and explicit sex education a right
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 – including grandma, grandpa, aunts and uncles.

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/recording methods
- Review of data
- RECOGNISE ADULT BEHAVIOUR MUST CHANGE

The ABC of behaviour

The ABC of behaviour

Objective, accurate observations essential

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<tr>
<th>Date</th>
<th>Antecedent</th>
<th>Behaviour</th>
<th>Consequence</th>
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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?
- Gain attention? Avoid activity? Seek excitement? Other
Can we understand the functions?

- Throwing things – during play, at meal times?
- Hitting or pushing others
- Pulling hair
- Ignoring
- Eating and drinking – difficult mealtimes?
- Difficult bedtimes
- Running off
- Refusal behaviours – avoidance, lying down on floor
- Grinding teeth – other noises
- Swearing?
- ?

Summarise results, devise a plan

- List possible functions – for avoidance?, attention?, control?, to reduce anxiety?
- Decide plans for:
  - Decreasing unwanted behaviours
  - Teach new replacement/alternative behaviours (skills)
  - What rewards can be used for positive behaviours and new skills?
  - What behaviour 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, undistracted, 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: coming in after playtime
  - Job: to do = hold door; give message, hold bell
  - Come in below bell
  - Hold hand before bell rings to prevent running
  - Reward for coming in when bell goes = child choose
  - Do not reinforce refusal = look away, do not show emotion, do not allow child to run off and do other things.
  - Check out classroom situation re 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 asks 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

Examples: 5 case studies and interventions

Strategies to address challenging behaviour in young children with Down syndrome

- Gareth and Sarah
  - Challenging behaviours linked with poor sleep
  - Noncompliance - refusal
  - Inappropriate hugging
  - Assistance
  - Self-stimulatory behaviours


Recommended reading and resources

- Right to Live CD 2004 - Down Syndrome Society of South Australia. Video/DVD - excellent series by Ben Graevenzaken
- 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

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Developing speech and language skills at home – 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 develops 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 at home and school
- 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 conversations with peers and family
- It is important to have targets for teaching new vocabulary and grammar and improving speech clarity

1. Assessment of vocabulary is important
Vocabulary size paces 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 to the word
- 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 you think he or she understands it

Choosing vocabulary to teach
- Personal interests – motivating words to teach
- Liaising with school – curriculum topics
- Personal books – outings, interests, conversation diaries
- 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
Summary (vocabulary) - targeting the profile

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

2. Grammar development

- Understanding grammatical concepts may begin when a child understands approximately 250 words
- Use DSE Sentences and Grammar checklist for assessment

Early grammar includes learning to use:
- 'ing'
- Prepositions in/on
- Plurals
- Irregular past tense
- Possessives
- Articles a/the
- Regular past tense

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)

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
Importance of expansion

- Importance of expansion as a language teaching tool
- It is a natural tool for teaching sentences and grammar – when children are at a 2 'keyword' stage, child says 'Daddy gone' and you say 'Yes, Daddy has gone'
- Or 'Mummy shoe' and you say 'Yes it is Mummy's shoe'
- When making personal books or conversation diaries – ask child to talk about the picture then take their key words e.g. 'play sand' and make shortest correction sentence 'I played in the sand today'
- This way you will be giving them the language for what they are looking at/thinking about – very important if they are to understand and remember it.

Sharing books

- Reading books together is a very powerful way to teach new vocabulary and sentences
- Repetitive reading of favourite stories
- Talking about the people and the activities in the book
- Most children with Down syndrome love to share books
- Give them time to take in information and join in
- Encourage pointing to the pictures as you talk about them
- Follow the child's lead – let them point and show their interest

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 (Rob 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>Strands</th>
<th>Duration</th>
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<tbody>
<tr>
<td>Reading Strand (20 mins)</td>
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<tr>
<td>Reading easy level book</td>
<td>2-3 mins</td>
</tr>
<tr>
<td>Reading new Instructional level book</td>
<td>5 mins</td>
</tr>
<tr>
<td>Sight word learning</td>
<td>2-3 mins</td>
</tr>
<tr>
<td>Letters, sounds, phonology</td>
<td>5 mins</td>
</tr>
<tr>
<td>Introduce new Instructional level book</td>
<td>5 mins</td>
</tr>
<tr>
<td>Language Strand (20 mins)</td>
<td></td>
</tr>
<tr>
<td>Vocabulary: Introduce new words</td>
<td>5 mins</td>
</tr>
<tr>
<td>Vocabulary: Reinforce meaning of new words</td>
<td>5 mins</td>
</tr>
<tr>
<td>Expressive language: Use new words in connected speech</td>
<td>5 mins</td>
</tr>
<tr>
<td>Expressive language: Use new words in written language</td>
<td>5 mins</td>
</tr>
</tbody>
</table>
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 images
    - Not necessarily completely new
    - Looked at both % know and % use ratings
    - Related to themes

Example from classwork

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

Introducing new vocabulary

Language Strand

- 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)

<table>
<thead>
<tr>
<th>Week</th>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
<th>Friday</th>
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<tbody>
<tr>
<td>1</td>
<td>Soup</td>
<td>Cereal</td>
<td>Chess</td>
<td>Lunch</td>
<td>Consolidation</td>
</tr>
<tr>
<td>2</td>
<td>Crunchy</td>
<td>Soft</td>
<td>On</td>
<td>In</td>
<td>Consolidation</td>
</tr>
</tbody>
</table>

- Work on base form but room to extend e.g. verb tenses

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

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

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

3. Child generates utterance containing new word

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

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Expressive language film clip

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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, bo, be)
- 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

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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

- Kumin, L. (2006) Helping children communicate better (ages 6-14); Woodbine House
- Buckley, S. (2001) Speech and language development - an overview
  - http://store.dseusa.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.dseusa.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

See and Learn - early intervention materials

- Visual supports for learning
- Language and reading from first words to sentences
- Speech from sounds to words
- Number coming shortly
  - http://www.readinglanguageeducation.com
- Further information
  - Email dse enterprises/rli
  - Blog seeandlearnblog.org
  - @SeeAndLearn

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Developing number and memory skills - at home and school

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

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?
- 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 Dsii 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' (Ramscale et al)

Teach vocabulary and basic concepts

Shape and colour words
Circle/square/triangle
Red, blue, yellow
Play matching and sorting games

- 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

A guide to steps in counting and calculating

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
- 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 to 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 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

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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 subituslable (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’ (Sannecke)
- 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 & Siegel 2009).

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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?’ to 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

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Extra visual supports for learning number words

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

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Visually support learning number sequences

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<tr>
<th>Line</th>
<th>1</th>
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- Practice different parts of the count sequence
- Rote count from other numbers than 1

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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 Stem 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 'ty's'
  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
Joe is drawing circles then counting them all

Teach addition with other strategies
- Visually support counting-on with a numeral
- With Numicon, spinner
- Visually support counting-on with a number line
- Make 'one more'
Number bonds – learn visual imagery to support
Strategies for subtraction, taking away
• 'Taking away', 'Counting-back,
  'difference' (counting forward)
  using a number line
• 'Chopping –off' using Numicon
• Recall of number facts, doubles
• Number sentences/stories

Place value – tens and units
• Stern 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

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. Westenberg (2007)

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

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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 & SPHT (BRIEF-P).

- Gains are sustained – children likely need more frequent practice. JM intervention programme less intensive than WM (73 activities v 200) – current case study of WM showing continuing gains.

- Planning a larger study in USA – to see if gains in verbal STM, language and academics

---

**Pilot**

- 5 Children with Down syndrome

  - Training zt: Mainstream Schooling

  - Cogmed training completed at home.

  1. RPMT (Rudimentary Picture Vocabulary Test)

  2. 8 Subtests of the WAIS (Verbal & Visual STM/WM)

  3. BRIEF parent version

  - Shown children could use the programme and supported a further study

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**Main Study**

- 24 Children with Down syndrome

  - 21 Mainstream, 3 SEN

  - Cogmed training completed at school.

  1. RPMT (Rudimentary Picture Vocabulary Test)

  2. 8 Subtests of the WAIS (Verbal & Visual STM/WM)

  3. BRIEF P - parent version (questionnaire)

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

  - Sae Bennett, S., Holmes, J., Buckley, S. (2013)

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**Resources and references**

- Numicon teaching kits:

- 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


- Horstemeyer, 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.downd-syndrome.org/research-practice/103/](http://www.downd-syndrome.org/research-practice/103/)

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**Additional resources**

- Numbershark CD and other teaching materials – [http://www.parentstoteach.co.uk/](http://www.parentstoteach.co.uk/)

- Range or software from Inclusive technology, [http://www.inclusive.co.uk](http://www.inclusive.co.uk)

- Time cracker Quality in Education Centre, Strathclyde University [www.strath.ac.uk/dse](http://www.strath.ac.uk/dse)

- See and Learn Number – developing See and Learn kits and apps to teach first maths concepts: size, shape, colour, patterns and first counting (to adding and subtracting 1-9) – coming 2014


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**Reading and references**


- University of York website about memory – for parents and teachers [http://www.york.ac.uk/exc/units/ideateachers.htm](http://www.york.ac.uk/exc/units/ideateachers.htm)


- Renscari, M. Dye, M et al. (2011). The enigma of number: Why children find the meanings of even small number words hard to learn and how we can help them to do better. PLoS One 6 (7) e22501.

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Developing literacy skills at home and school

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 and taught by parents
- 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 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 student’s 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)

Personal book (film clip)
1. Book reading

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

Supported reading

2. Sight word learning/whole word reading

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

Start with sight words, personal books and reading for meaning
Sight words – teaching activities

- Matching, selecting, naming
  - football
  - 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
- Pairs games (pelmanism)
- Pictures

2. Sight words – which words?

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

2. Sight words: use in sentences

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

Film clip – word in simple sentences

Using sight words in expressive language
3. Letter sound knowledge

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

4. Phonics and phonological awareness

- Listening to sounds and linking letters and sounds
- Listening to sounds (phonology)
  - Use visual support where helpful (pictures/objects)
  - Rhyme
    - Rhyme matching/pelmanism game, rhyme oddity, rhyme production
    - Works with pictures/objects/word cards
  - Phonemes
    - Discriminating initial/medial sounds
    - Matching and sorting game: ask child to match pictures or objects based on starting or ending with the same sound
    - Visual support: 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’: e.g. What word is the toy saying? ‘c-a-f’
    - Use pictures for support (cat, dog, hen...child points to correct one) but move on to listening only as child succeeds with pictures
  -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)

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, 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 (di-o-gi) 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/infering
  - Use of modelling and scaffolding
- Questioning
  - Answering questions and formulating questions
  - Natural discussion
  - Expressive demands – support e.g. give choices, picture selection tasks, written questions, etc.
- Strategies
  - Look-back
  - Using context (including pictures)
  - Link to world knowledge and personal experience

Comprehension support during reading

Matching sentences to pictures
Comprehension activity

Materials for showing understanding and for retelling a story

Wreck of the Zanzibar – story board

Learn to refer back to text to find the answer

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

Ordering words to form a sentence (film clip)
Making a sentence with word cards

Go Away, Cat

Examples of spelling activities

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

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
  - See some software links in resources

8. ICT

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

- Make reading fun
  - Use a variety of activities and 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
- Other principles which have been used
- RLI has the added benefit of using language measures on the programme—see Burgoyne et al. paper in resources list
- RLI Handbook and Resources published with video
- Over the last school year we implemented RLI in a pilot project in Texas—can be used in US schools with positive outcomes for both reading and language
- Training educators across Texas at present and RLI accredited US based trainers
- Web-based training available

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
- Widget software and apps — using symbols (Don Johnston US)
- Inclusive technology — UK and USA
http://www.inclusive.co.uk/
- Specialiapps — See and Learn apps iPad and Android UK and USA
http://www.specialiapps.co.uk/en-gb/
Introducing RLI

Further information about RLI:
- DSE web site: http://dseint.org/RLI
- Scientific paper reporting RCT: http://dseint.org/QXBO6Z
- Online events: http://dseint.org/ZipWxP
- New RLI blog: http://dseint.org/2MMyZs
- RLI email group: http://dseint.org/RAHtdP

Handbook
- From UK store: http://dseint.org/YRGluy
- From US store: http://dseint.org/XoY1Cu

See and Learn – early intervention materials

- Visual supports for learning
- Language and reading from first words to sentences
- Speech from sounds to words
- Number coming clearly
- Further information: see our website: http://dseint.org/RLI
- Blog: seeubley.org
- DSE4Talk

The RLI handbook

- Instructions for how to deliver each component, ideas for teaching activities and adaptations to suit individual abilities
- Practical information on delivering intervention, record keeping and collaboration
- Resources for assessments and teaching, planning and record keeping
- Video illustrating each component and activities for teaching, including examples of children with different needs
- Background information on development and evaluation
- More information: http://www.dseint.org/rli

References to RLI and blending study

- See http://www.dseint.org/rli

Practical guides and resources

- Horsemeets D. (2011) 'Reading again: how to motivate and teach older beginners ages 10 and up. 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

Supporting independence or (or being allowed to Become an Adult)

- What do you value most in your life?
- Take 5 minutes to think about this and do not confer with anyone else
- Make a list and put in priority order if you can

- What do you fear the most – if things were to change in your life?
- Again no conferring and prioritise please

Parenting other ‘typical’ children?
- What do you hope your other children will achieve in their adult lives?
- In priority order?
- You can confer with spouses/partners...

Parenting a child with Down syndrome
- What do you want for your child with Down syndrome?
- In priority order?
- You can confer with spouses/partners...

Do we accept differences?
- Try to forget about the barriers we may have to overcome
- What should we want for our sons and daughters with Down syndrome?
- What do they want?
What are the barriers?

• Write down a list of the barriers to an ordinary life as you see them
• Please do not confer

Why am I doing this?

• Because my daughter forced me to rethink and change my expectations from her teenage years
• My mother in her 80’s made me rethink
• Because Roberta has shown me the benefits of being allowed to be an adult
• Because I sat in a sharing session at NDSC a few years ago and wanted to cry as I heard how many young adults with Down syndrome were not being listened to, respected and allowed relationships and fully adult lives.

Roberta and Andrew

Roberta and Andrew – the benefits

• Practical – the coin operated phone
• Cognitive – the birthday story and the ability to plan ahead
• Social – able to go out without a ‘minder’ from staff or family
• Therefore ability to take control of her own life
• Complementing each other in social skills
• Self-confidence
• Change of self-identity

Not a happy ending

• Roberta and Andrew enjoyed a very happy relationship for some 4 years
• They went on holiday to Malta
• They sometimes shared Andrew’s bedsit
• Attempts to set them up in a flat were not OK with Andrew’s family
• He was forbidden to see Roberta, the relationship broke down
• Both were devastated – Roberta took 2 years to recover

Roberta and Mark
Ten years later...

- Roberta meets Mark, a young man with Down syndrome
- They have enjoyed a stable and loving relationship for 5 years
- They share a flat in a supported living setting and have lived together successfully for 4 years
- They are inseparable
- The way they love and look after each other would put many 'typical' couples to shame

It has not been easy for them

- Mark had some serious health problems in 2008
- The Emergency room story, the hospital and the follow up
- Do not underestimate understanding and competence because of poor expressive language skills
- Roberta has developed some serious health problems – she has an arthritic hip – and now uses a walking aid and wheelchair

It has not been easy for them

- She has Inflammatory Bowel Disease – treated since late 2009
- the symptoms (chronic diarrhoea) are difficult to control and create hygiene and toileting problems. They cope exceptionally well.
- Mark is always patient and caring – practically and emotionally
- It has put pressures on him – they deal with it ‘not Mark, Mum it's the staff!’
- 'Roberta is a calming influence' - Mark's mum
- 'It's great to see them communicate and share a joke together – first real intimate friendship for Mark' – Mark's brother

The holiday chalet hot tub!! July 2012

Is Roberta exceptional? No

- At 17 very limited skills
- Began to change my thinking as a teenager
- Reached puberty at 13 – without anticipated problems
- Wanted to wear jeans to school and sit with boys in bus
- Watched same soaps and pop groups on TV – the bedroom frieze story
- Same social and emotional needs – forget mental age

So how do we deal with barriers?

- Our own attitudes???
- The ‘Peter Pan’ syndrome...of 100 years ago?
- 'they are Peter Pan children – perpetual children, never grow up’ – my mum was told....
- Isn’t this still the case for many adults with Down syndrome - BECAUSE WE DO NOT ALLOW THEM TO BECOME ADULTS?
- CHANGE NEEDS TO BEGIN AT HOME – attitudes need to be confronted and change
Services

- Does the law in USA need to change to enshrine the right to be a full adult citizen?
- Voting rights?
- What needs to happen in services?
- What needs to happen in funding mechanisms?

- We all need to fight for these changes – we live in a democracy – you get the services you campaign for
- This is the last taboo ....

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 maths 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

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

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

Planning for work and leisure

- Individual curriculum
- Reflecting strengths and interests
- Reflecting work aspirations and choices
- Should bring academics and life skills together
- Madison High School example – blending academics and life skills and inclusion
- Learning is lifelong and most students with Down syndrome continue to learn literacy and math in adult life – no ceilings please
Inclusion – learning in classroom

Inclusion across the curriculum

Inclusion in science

Acquiring ICT skills

Inclusion in music

Health eating – healthy life style

- 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/growth/healthcare
- Joan also maintains Disability Solutions – much helpful material
  http://www.disabilitysolutions.org/
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

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

What are you going to do to change?

- What steps will you take today, tomorrow, next week?
  - In your family?
  - In your community?

What do DS organisations need to do?

- What steps will you take today, tomorrow, next week?
  - In your community?
  - At county level?
  - At government level?

A life and love like everyone else

Reading and resources

- Dsii Adult series of books on all adult living topics
  - http://store.dsusa.org/collections/books/adults