Down Syndrome Education Conferences

Parent Track
Ages 0-6

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

Thank you to our conference sponsors!

Parent Track
Ages 0-6

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

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

Westin Crown Center
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.

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<td>Keynote: What are the priorities for parents - the view from research and from personal experience as a parent</td>
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<td>Sharing books and supporting reading development at home</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
5960 Dearborn Street, Suite 100 Mission, KS 66202

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

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

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

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

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

Seminars sponsored by:

[Image of seminar sponsors]
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!

314-878-2105

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Down Syndrome Education International

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

Keep in touch with our work

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

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
- I met her at 9 months of age
- Fostered at 16 months
- Adopted at 10 years
- Left home at age 22
- Partner at 23

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

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

Teenage years with family

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 legally 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 26-30 than in previous 15 years.
- With Andrew she had social independence - could plan her own life - go out without staff or family
- We understand who we are and our place in the world by the way we are treated.

Roberta taught me not to underestimate understanding

- The biggest difficulty that most children and adults with Down syndrome face - on a daily basis - is not being understood because they cannot put into words all they know and want to say - imagine how that feels
- Since Roberta reached adulthood she has constantly surprised us with her understanding and competence
- The way she has managed her life and relationships
- The way she has coped in emergencies - Mark has been in hospital as an emergency admission twice - the only person who could keep him calm and get him to let the doctors help was Roberta. She even had procedures first to show him it was OK and sat with him for many days (she probably has an IQ of 30-40/???)

What has helped Roberta to succeed?

- Social competence and confidence - an extrovert
- The ability to learn the social rules and behave in socially appropriate ways in different settings such as at home, in school, in church, in a cafe or on the bus - this requires the ability to control one's emotions, impulses, desires and behaviour
- The ability to make friends and maintain relationships - this requires the ability to understand other people's behaviour and feelings and react appropriately
- Social competence determines the quality of life of any person - and is not predicted by mental ability
- It is learned through social experience

What else would have helped her?

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

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 DSPE 9 (3) on website)

- Hearing and Vision
- Social understanding, empathy & social skills
- Speech and Language
- Motor Skills
- Verbal short-term memory
- Self help and daily living skills
- Learning from listening difficult
- Information processing
- Visuocompetence
- Number
- Visual learning a strength
- Weaknesses
- Non-Verbal Mental Age
- Reading
- 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

- 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

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

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

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

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

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/
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

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.dseentreprises.org/ for all the above items

THE EVIDENCE FOR A SPECIFIC PHENOTYPE OR PROFILE

- See Deborah J Pickard (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) 18, 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 http://www.down-syndrome.org/research-practice/
Developing speech and language at home – early years

Overview
1. Language learning
2. Encouraging pre-linguistic and non-verbal skills
3. Using signs
4. Teaching vocabulary
5. Teaching grammar
6. Developing clear speech
   - The ability to produce speech sounds influences vocabulary and language development therefore work on speech is equally important from the first year through childhood
   - Language and speech work should proceed in parallel

1. Language profile - research update
- Communication skills are usually a strength
- Early vocabulary development is delayed
- The pattern of vocabulary development is the same as in typical development
- Typically developing children and children with Down syndrome show huge individual variability with vocabulary development
- Expressive difficulties become greater with increasing age for children with Down syndrome
- Vocabulary pasts grammar, just as in typical development
- Most children with Down syndrome are combining words and/or signs by 5 years of age.

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

1. Language intervention
- Language is learned every day in natural situations as you talk to children – so the first thing to stress is the importance of talking to your child. The quality and quantity of talk influences language progress for ALL children.
- In addition – children with Down syndrome will benefit from explicit teaching of vocabulary and grammar
- This gives them more opportunities to hear and to learn words – more practice and repetition are needed
- Language learning begins in the first year of life and continues throughout life with the early years being a very important time

2. Pre-linguistic skills – babies & toddlers
- Pre-linguistic skills serve as the building blocks for language development and learning
  - eye contact
  - gesture use
  - imitation
  - joint attention
  - turn-taking
- Improved pre-linguistic communication will enable pre-linguistic children to communicate more effectively and lead to better language skills later on
- These non-verbal 'pivot' skills continue to be important when children have started to talk
Film clip – early imitation – 4 months old

Teaching early vocabulary
- Understanding comes before expression
- Use DSE Vocabulary checklist – first 120 words – to select words to teach and to record progress
- Have separate targets for words to understand and words to say – targets may be very different
- Make it visual – objects, pictures and signs
- Structured practice – short bursts
- Extra practice in natural ways – e.g. play
- Start with nouns and verbs and then move on to include a variety of words e.g. adjectives, prepositions
- Matching-selecting-naming games – See and Learn

Using gestures and signs
- Evidence suggests that teaching signs increases early vocabulary
- Many children can sign words before they can say them
- Signs hold the child's attention and can be a clue to the meaning of the word
- Signs can be used when talking to babies from 8-9 months
- Always say the word as you sign it
- Remember you are using signs as a bridge to talking
- The focus should be on teaching the child to talk
- Our data shows that signs are steadily dropped as the child begins to say words
- Note cautions about later use of signs at end of slides

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

See and Learn – picture matching

Teaches matching, selecting, naming
- Matching – child matches picture to picture while hearing and learning the word
- Selecting – child chooses the picture when you say the word – so demonstrating comprehension of the word
- Naming – child can name picture
- This is a very effective procedure for teaching words, colours, numbers, shapes......
- Most children will be able to select many pictures correctly showing that they are understanding the words long before they can say them without a prompt
- Important to record what they understand and keep teaching new words for their cognition
See and Learn Language and Reading

1. First Words Pictures
   - 68 first vocabulary pictures and matching baseboards
   - Guidebook, instructions and record sheets for activities
2. First written words
   - 16 written words, 20 phrase cards, matching boards, 9 books
   - Teaches range of 2 ‘key-word’ phrases
3. More Words Pictures
   - 55 more first vocabulary pictures and baseboards
   - Instructions and guidance for activities
4. First Sentences
   - Introduces 16 more written words within simple sentences and
   - in 4 books - teaches a range of three ‘key-word’ sentences

Special words app – match pictures, hear word

Special words app – match picture to word

www.Specialiapps.co.uk

Special words – first pictures and words from See and
Learn Language and Reading program
- Adaptable, you can add your own pictures and words
- Available in many languages
Special stories – for creating personal books
You can get the See and Learn Language and Reading
books from our website to download into Special Stories
Apps and software play to our children’s strengths as visual
learners
Very powerful learning tools but learning from app must be
generalised to everyday use

Encouraging Word Production

- Choose words the child already understands
- Modelling and imitation
- Give choices
- Create opportunities for the child to communicate
- Respond to all word attempts
- Allow extra time for responses
- Keep a record
- Use DSE vocabulary
  - checklists – include instructions

Film clip – teaching vocabulary
Film clip – Understanding pronouns – 4 years old

Language Development
- First words
- Combining two words
- Grammar

Language and Grammar - research
- The same 2 and 3 word combinations as typical development
- Average age for emergence of 2 word phrases - 3 years old (Kumin, 1999)
- Expressive grammar - particular area of difficulty (understand and express concepts, but are not using the morphological markers (e.g. plural 's', past tense 'ed', possessive 's'))
- By 3 years old many will understand early grammatical concepts although not able to use the grammatical markers until about age 5. (Kumin, 1999)
- May be linked to speech difficulties

Developing knowledge networks
- The first 100+ words children learn are for people and activities in their daily word – common in all languages
- As their vocabularies expand they will learn words more easily if they can link them with words they already know so teach in themes
- Research shows that they learn words faster in a context
- Make sure you teach a range of words nouns, verbs, adjectives, pronouns, prepositions etc (DSE vocabulary checklists provide a guide)
- Also very important to teach category words for linking words by meaning and supporting memory

Film clip – category words – 4 years old

Language and grammar - intervention
- Modelling
- Imitation and expansion
- Use of signs
- Pictures/props
- Pacing boards
- Repetition and practice
- Conversation diary
- Sequencing cards/games
- Focused personal books (e.g. plural book)
- Open-ended questions (e.g. tell me more..)
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 correct 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

Importance of daily communication

- The extra teaching games will make a difference
- Daily repetition and practice
- But children learn to talk because we listen to them and they can effect their world – ask for things, tell you how they feel
- It takes children with Down syndrome longer to plan and say words and sentences – we need to give them time
- We need to sensitively support daily talk and be sure to respond to all communication attempts – any sounds or gestures – to encourage more
- When children are late to talk and say few words they get talked to less and have fewer learning opportunities

Speech development – start early

- Starts early in typical development:
  - In typical development, children are learning to discriminate sound in the first year of life – tuning in to native language
  - High incidence of hearing loss
  - Phonological difficulties
  - Verbal short term memory difficulties
  - Poor auditory processing
  - Differences in anatomy and physiology
- SPEECH WORK MUST START EARLY – as research shows sound production ability influences first words in language development (Stoel-Gammon 2011) - and continue through childhood
- Principles similar for older children

Intervention

Listening practice
- develop phonological system
- typically developing children develop this in first year of life
- children with Down syndrome need practice and repetition

Practical activities
- Sound cards
- Sound games (boo)
- Symbolic sounds (bmmm-bmmm; choo-choo; bas; moo)
- Talking/singing

Film clip – sound cards – one year old
Intervention

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

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

Film clip – discrimination – 2-1/2 years

Intervention

Production practice
- allows for voice exploration
- voice has power and meaning
- turn-taking for conversation – speaker/listener

Practical activities
- single sounds/sound cards
- babble
- symbolic sounds
- consonant-vowel combinations – ba, bo, bee
- simple words
- syllable marking – 1, 2, 3, 4 syllable words

Film clip – syllable marking – 4 years old

Intervention

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

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

Some evidence this approach is effective for children with Down syndrome and can improve phonology quite quickly (see Dadd, NI Chisholm refs) See and Learn Saying Words kits based on this work.

Film clip – auditory bombardment – 2 yr old
Intervention

Sorting by initial sounds in words
- Listening practice - draws attention to initial sounds in words
- Production practice - draws attention to sounds in words
Practical activities
- Sound books/boxes - sorting by initial sound
- I spy game
Note these are phonological awareness activities and will help speaking and reading.

See and Learn Speech

Six steps (packs):
- Step 1 - playing with sounds
- Step 2 - putting sounds together
Available
- Step 3 - saying words
- Step 4 - saying more words
- Step 5 - saying later words
- Step 6 - saying syllables in words
2014 - in kits and apps

See and Learn Playing with Sounds

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

See and Learn Putting Sounds Together

Resources:
- Picture cards representing consonant-vowel combinations (e.g. bee, key, tea, pea, sea)
- Picture cards representing symbolic sounds (e.g. brum brum, chew chew)
- Record sheets
Activities:
- Using sound cards and picture cards as visual cues to prompt production of sound combinations

Oral motor skills

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

- Developing spoken language should be a priority – at home and in preschool
- The number of words a child knows matters – vocabulary teaching should be planned and progress recorded until at least 600 words are spoken
- Use visual supports – objects, pictures, signs
- Use ‘expansion’ to teach sentences and grammar
- Make full use of story books and personal books
- Communicate naturally with your child at every opportunity
- Work on speech discrimination and speech clarity

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

References/Resources – speech

- DVD – Speech and Language activities for preschool children with Down Syndrome – available at webdysedusa.org

DSE Language Resources

- DSE checklists for speech, vocabulary and grammar – http://store.dseusa.org/ in print and digital versions. Use to choose words to teach and monitor progress.
- Development in Practice DVD – Activities for babies with Down Syndrome – available from http://store.dseusa.org/
- Development in Practice DVD – Speech and Language Activities for Pre-School Children with Down Syndrome – available from http://store.dseusa.org/
- Down Syndrome Issues and Information series of books – Speech and Language available at http://store.dseusa.org/
- To be updated 2014

See and Learn and special apps

See and Learn apps for apple and android in UK and USA http://www.specialapps.co.uk/en.php
Special Words – teaches See and Learn vocabulary and you can add your own pictures and words
Special stories – enables you to make personal books with photos and text – it is easy enough to be used by children.
Developed by ICT experts who also happen to have a son with Down syndrome – Both apps have won awards
See and Learn More Sentences - 2014
See and Learn Letters and Sounds – 2014
Kits to download and make plus DSE app versions of kits 2014

References

**Play, number and cognitive skills for young children with Down syndrome**

- Sensory play
- Exploratory play
- Cause and effect
- Pretend play
- Imaginative play
- Co-operative play

**Types of play**

- Sensory play
- Exploratory play
- Cause and effect
- Pretend play
- Imaginative play

**Cognitive skills**

- Exploration skills
- Imitation skills
- Object permanence
- Cause and effect
- Symbolic play
- Problem-solving
- Discrimination/classification
- Sequencing

**Play partner**

- Children with developmental delays may get 'stuck' in repetitive play
- Children with Down syndrome need play partners even more than other children – people to join in their play and support them in play
- They may be more dependent on others to show them the next steps and how to play
- Practice and repetition

**Children learn through play**

- How things work in the world
- How to manipulate things
- Build strategies
- How to think, plan and solve problems
- Consolidate all that they learn from their everyday lives
- Play shows how much they understand about their world
- The process of play is important, not just the outcome

**Play skills and Down syndrome**

- Play partner for longer
- Gross and fine motor delays
- Need for modelling and imitation
- Risk of opting for social games rather than problem-solving
- Language learning opportunities in play
- Experiencing a range of types of play

**Gross and fine motor delays**

- Motor skills support play in a variety of ways
- Children with Down syndrome need more opportunities to practise different kinds of play, but delayed motor skills may interfere with this
- Take note of interest through looking, attention and pointing and provide variety and opportunity in play
- Help them to do some of the things their gross and fine motor skills don’t allow them to do – e.g. shape sorters.
Need for modelling and imitation

- Children with Down syndrome need to see it, experience it and practise it over and over again before new skills are spontaneously used in their repertoire.
- Imitation is a strength area for many children with Down syndrome and a great way for them to learn.
- Modelling new skills highlights their strength in visual learning.
- Turn-taking games

Social games

- A strength in social skills allows children with Down syndrome to ‘opt-out’ of more difficult tasks rather than problem-solve or try new strategies.
- Provide support within new tasks for new activities – prompting and guiding correct responses until the task can be completed without the support.
- Modelling, turn-taking and shared participation may help.

Language and play

- Play provides opportunities for language learning and communicating together.
- Pretend play provides opportunities for repetition and practice of language they experience everyday – e.g., eating, sleeping, drinking, washing.
- Play provides opportunities to link ideas together for two and three word phrases.
- Pretend play allows for practising of foundation skills for sequencing and problem-solving – linking ideas together.
- Requesting games promote communication.

Developing attention skills

- Notice the child’s attention across different types of activities.
- Look for preferences.
- Look at ways of reinforcing and maintaining attention – individually, in a small or large group.
- Use visual and social strengths – pictures, signs, photos, gestures, peer support – to support attention.
- Use music, songs, and movement.

Following the child’s lead

- Join in their activity and what they are enjoying.
- Try to understand the play level they are at and what they are learning from their play.
- Copy what they are doing – wait until they watch you and then begin to ‘play together’.
- Move forward just enough for child to copy and join in – ‘scaffolding’.

Mastery motivation / Intrinsic motivation

- The desire to succeed through intrinsic motivation and enjoyment of learning rather than reliance on external motivation and rewards.
- Intrinsic motivation is important for learning – for perseverance and problem-solving.
- Teach and support problem-solving – cause and effect toys, shape sorters, puzzles, nesting boxes – chain 1, 2, 3 steps.
- Allow freedom to explore.
- Allow the child to initiate activities and interactions.
- Follow through on developmentally challenging activities.
- End activities in a positive way even if it is supported.
Teach and show – don’t test

- Children with Down syndrome have a strength in social understanding and are quick to realise when they are being tested
- This sets up a ‘pass/fail’ situation
- Model and show activities, guide with ‘errorless learning’
- Allow them the time and space to let them show you what they know with no pressure
- Provide support when necessary and then fade support as the skills improve

Know when to stop

- Pay attention to cues about participation in activities
- Is there a better time of day to do structured work?
- How long can children maintain their attention?
- Are they hungry, tired or uncomfortable and not able to tell you?
- Short bursts of structured activity throughout the day are just as effective as longer, drawn out activities

Allow extra time – be patient

- Research suggests that children with Down syndrome have slower rates of responding
- This can lead to an underestimation of a child’s skill and knowledge
- Allow extra time for a child to receive information
- Give children time to process the information
- Give time to organise and execute a response
- This allows them to demonstrate what they know
- This allows you to challenge them appropriately

Prepare the learning environment

- Provide an environment that invites exploration and supports incidental learning through observing, exploring, speculation and making discoveries
- Allow exploration that may be different to the adult’s goals and expectations – don’t intervene too quickly
- Multi-tasking – using one activity to target several different skills and concepts
- Give activities a purpose and a structure
- Encourage generalisation of skills across different activities

Pre-linguistic Milieu Teaching

- Promotes language development by teaching parents to engage in highly responsive interaction throughout daily routines
- Increases the frequency and complexity of intentional nonverbal communicative acts – sets the stage for later language learning
- Targets pre-linguistic skills – gestures, joint attention and eye-gaze shift
- Increases requesting and commenting

Effective for children:
- at a mental age of up to 9 months
- children who produce 10 or less words or signs
- children who understand less than 75 words


Hanen approach – fostering language through everyday experiences

A practical approach that helps parents learn how to foster their child’s language development during everyday routines and activities.
- Parents learn how their child communicates and her/his stage of communication
- How to turn everyday activities into opportunities for their child to learn to communicate
- Effective strategies that will help their child learn to communicate
- How to talk so their child can expand her/his understanding of language
- How to play, read and use music with their child to enhance her/his communication development

Hanen approach + structured, repetitive practice will benefit children with DS

http://www.hanen.org/

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Responsive teaching – Mahoney, MacDonald

- An early intervention curriculum designed to address the cognitive, language and social emotional needs of young children with developmental delay
- Implemented by parents and other caregivers
- Supports and enhances child development
- Encourages children to develop and use 'pivotal behaviours' that are foundations for development
  - social play
  - imitation
  - problem-solving
  - conversation
- http://www.responsive-teaching.org/

How number skills develop typically

- Social experiences and pre-school exposure
- Practical materials to support understanding - importance of practice and rote learning of basics
- The relevance of the skills to everyday life
- Motor skills for counting and recording (writing numerals)
- Knowing the language and concepts for maths
- Working memory capacity
- Logical reasoning ability

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Teaching number skills

- Principles for teaching number are the same as for all children – understanding progresses in the same order
- BUT we need to take into account the language and verbal memory difficulties and use strengths in visual learning
- Use visual supports (e.g. numeral cards, number lines, number squares, Numicon and Cuisenaire rods)
- Break tasks into small steps with lots of repetition
- Vocabulary - may need working on explicitly, as concepts may not be understood
- See and Learn Number in development – out 2014

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Practical activities

- Language environment – displays, books, songs, conversation, use number words in play and real activities
- Play counting games
- Use number lines
- 1:1 correspondence
- Match – select – name numbers
- Play quantity games – how many?
- Teach maths vocabulary words
- Introduce Numicon shapes and games

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Early math vocabulary

- Size
  - big, small
- Colour
  - matching games
  - sorting games
- Shape
  - Circle/square/triangle
  - Shape sorter/posting box
- Quantity – more, lots, some

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Film clip – early counting skills

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Need to master counting principles

- 1:1 correspondence
- Stable order
- Cardinality

Activities to teach counting

- Play counting games, sing songs, share books, use displays, play board games
- Use visual support of number line to learn number words in stable order
- Start with 1-5 in saying words, 1-2, 1-3, 1-4 in sets
- Play correspondence games with toys/objects to practice one-to-one correspondence
- Share items and compare sets – ‘more’, ‘less’, ‘same’
- Play ‘give me’ games and end counting games with ‘How many?’ to teach cardinality
- Introduce Numicon – visual-spatial representation of number

Extra visual supports for learning number words

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

Numicon shapes explain numbers

- An accurate visual-spatial representation of numbers
- Number shapes clearly show:
  - that each next number is one more equal unit
  - and the relative size of different numbers

Numicon activities

Cover the board

Other activities:
- Playdough – press shapes into playdough and name
- What’s in the bag? – choose shapes out of a bag and name
- Cut-outs – cut out Numicon shapes, colour and name
- Hide and find Numicon shapes

Numicon activities

- Matching shapes
- Matching numerals to plates
- Selecting plates by name
- Matching plates to a number line
- Ordering plates
- Matching plates to appropriate quantities of items
Numicon activities

- Jumbled shapes
  - Model arranging the shapes in order – 1-5 at first
  - Jumble up the shapes, the child arranges in order
  - Increase to shapes 1-110
  - Fill in the gap
  - Swaps
  - Simple addition

Baddeley's 2006 Working Memory Model

Central Executive

- Phonological loop
- Episodic buffer
- Visuospatial scratchpad

Auditory memory difficulties

- Hearing loss
- Poor discrimination skills
- Poor phonological representations constructed
- Slow development of clear speech
- Less familiarity with words
- Slow retrieval of phonological information
- Slow organisation and production of words
- Lack of rehearsal strategies

Interventions – memory training

- Memory games – remembering 1, 2, 3 items
- Pairs games
- Kim's game
- Rehearsal training
- Sorting/category games
- Activity recall
- Interventions for improving phonology and speech (previous slides in speech intervention)

Interventions – supporting memory

- Props for remembering and recall
- Pictures
- Pacing boards
- Written information
- Practice in daily activities
  - Following instructions
  - Delivering messages
Film clip – memory – 3 years old

Resources and references – memory

Resources and references – play/cognition
- Hanen approach – It Takes Two to Talk; [http://www.hanen.org/web/Html/PartnersPrograms/ItTak eTwoToTalk/tabid/76/Default.aspx]

Resources and references – Numicon
See and Learn Number – to teach first shape, size and colour concepts, how to classify, make a sequence and to count items 0 to 9, understand numbers indicate quantity, ordinality (each next number is 1 more), cardinality (the last count word tells how many you have), compare sets (same or different), add and subtract. (Supports development from 2 years to primary school). In development at DSE – out 2014
Numicon teaching kits from DSEUSA store:
- 1st Steps with Numicon at Home is a starter kit for parents
- Numicon Firm Foundations Kits – One to One and Class kits
- See [http://store.dseusa.org/collections/numicon/numicon-kits]
Information on Numicon see [http://www.numicon.com/index.aspx]

Resources and references – play/cognition
Developing early reading skills at home

Teach reading early – why?

Reading for children with Down syndrome

The benefits of developing reading

Overview

1. Teach a small sight vocabulary first

Whole word reading

First steps to literacy from 2 years

1. Teach a small sight vocabulary
2. Use these words in sentences
3. Ensure the sentences can be read and understood
4. Teach text comprehension strategies
5. Practice formulating sentences
6. Use Personal Books
7. Develop phonics skills
8. Make activities fun and motivating!
9. Start RLI for 5-6 year olds
Word matching (film clip) 2 years 5 months

Word selecting (film clip) 2 years 4 months

Word naming (film clip) 3 years 10 months

2. Use these sight words in sentences
- From the beginning choose words to make simple grammatically correct sentences.
- Select words as appropriate for the child's language comprehension level and interests, starting with words that the child already understands.
- Always read the words and sentences with the child while they are learning — that is use errorless learning techniques to support success.
- Make books using pictures of the child's own world and interests to illustrate the sentences.

Simple sentences (film clip)

3. Ensure words and sentences can be read and understood
- From the start ensure that the child is reading for meaning.
  - Can read word and match to correct picture
  - Can read sentence and match to correct picture
- In books
  - Use of pictures to support understanding of text
  - Act out sentences/match to pictures to ensure understanding
- Once the child is enjoying the reading activities with familiar vocabulary, introduce new vocabulary and grammar targets into the reading
- Always be ready to prompt to support success but give child time to respond first
4. Teach text comprehension strategies

- Sequencing – familiarity with concepts and language (first, next, last), start with sequences/routines that the child is very familiar with e.g. Daily routines (bath time, brushing teeth), favourite nursery rhymes and stories.
- Retelling/repeating – repeating sentences the child has read, asking the child to repeat sentences you have read, use of carrier phrase activities.
- Summarising/commenting – ‘my favourite part was ....’
- Questioning
- Use of modelling and scaffolding

5. Practice formulating sentences

- Matching the key word in a sentence
- Matching all the words in a sentence
- Ordering words to form a sentence
- Choosing words to make own sentence
- Filling in the missing word

6. Personal books

- 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

- Examples of this type of book include:
  - Carrier phrase books – I like..., I can...
  - Conversation diaries
  - Topic books
7. Teaching phonics

- Start to teach phonics once the child has a sight vocabulary of 30-40 words (pre-schoolers) or with the rest of the class in school.
- As with all activities using visual supports is key e.g. pictures, plastic letters, whole words.
- Many of the early phonic skills will overlap with speech activities e.g. Letter sounds, initial sounds in words.
- See and Learn Letters and Sounds coming soon – evaluated with 4 year olds – teaches letter sounds 6 at a time to make rhyming words e.g. cat, hat, mat, bat.
- An easy way to start phonics and we were surprised at the children’s progress.
7. Phonics is important
- Children learn to read using a variety of strategies
  - Sight word learning to get started and for the many irregular words in English (yacht, island, was.)
  - Context – guess the 'new' word by choosing a word that gives correct meaning or grammar in sentence
  - 'Sounding out' – sound out the letters in an unfamiliar word in the book and try to 'blend' them to identify the word – this is using phonics
  - Phonics is also very important for working out how to spell a word – the faster children understand phonics the faster they progress as readers

7. Component skills for phonics
- There are three important component skills
  - Phonological awareness (PA) – the ability to hear sounds in words
  - Letter sound knowledge – learning the sounds represented by letters
  - Using letter-sound knowledge and PA to work out a printed word by 'sounding out' and 'blending'
Children need to be taught all three
- Studies show children with Down syndrome use their strong sight word skills to support their reading for longer than other children but many do master and use phonics
- US research (Kemper et al.) showed children with Down syndrome with more sight vocabulary learned phonics faster

7. Phonological awareness
- 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 images: ask child to find objects in a picture that start/end with a certain sound
      - Play 'I say (something beginning/ending with)'
      - Listen to spoken word pairs, do they start/end with the same sound or not?

7. Phonics and phonological awareness
- Blending
  - Use phonemes the child knows
  - Use a toy to do 'sound-talk': TA does the sound talking – What word is the toy saying? 'e-a-a-
  - I-say with a few objects e.g. TA says, I spy with my little eye a 'p-e-e-

- Segmenting
  - Use phonemes the child knows
  - Use a toy to do 'sound-talk': child does the sound talking – TA says, "Can you say 'at'?" in sound-talk? child says, 'c-a-a-'""n
  - Phoneme framing: ask the child to sound out a word (e.g. dog) and put a coty counter into the frame each time a sound is said

7. 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, slice the letters gradually closer to one another; the child says the letters faster together, until they blend them into the whole word
  - Give them flashcards with words and ask them to sound them out (k-a-t). 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
Film clip – early blending – 4 years old

8. Make activities fun, model correct responses and prompt success
   - Make reading fun and meaningful
     - Use a variety of activities and/or presentations
     - Choose words and sentences that relate to the child’s interests or knowledge from everyday life
     - Be enthusiastic!
   - Play games and activities with the same vocabulary to support understanding and recognition.
   - Use errorless learning – ensure lots of practice and experience before introducing testing.
   - Children with Down syndrome can be sensitive to failure and we want to guarantee their success and motivation.

RLI – Reading and language program
   - We have designed and evaluated a school reading and language program which incorporates these principles
   - Progress was significantly faster on key reading and language measures on the programme
   - Younger children (5-6 years) made faster progress
   - RLI Handbook and Resources published with video
   - An RLI pilot project in Texas shows RLI can be used in US schools with positive outcomes for both reading and language
   - Training educators across Texas at present plus RLI accredited US based trainers and offer Web training
   [http://www.dseusa.org/en-us/resources/teaching/rl/]  

RLI Programme Structure
   - Daily 40-minute individual sessions, delivered by trained teaching assistants
   - Teaching sessions (1 to 4, 6 to 9): routine structure
   - Consolidation sessions (5 and 10): reflect and revise
   - Two interactive components
     - Reading Strand
     - Language Strand
   - Prescribed programme
     - Set out in manual
     - Opportunities to tailor sessions to play to individual’s strengths and address weaknesses

Resources
   - See and Learn Language and Reading
     - First Written Words
     - First Sentences
     [http://store.dseusa.org/collections/see-and-learn-language-and-reading]
   - See and Learn apps for iPad see at
     [http://www.specialapps.com/en_us/]
   - Down Syndrome Issues and Information books on Reading
     - see [http://store.dseusa.org/collections/books/reading](http://store.dseusa.org/collections/books/reading) (to be updated 2014)

Resources
   - Also videos showing preschool and primary readers from our work over last 25 years now available as DVDs
We can all make a difference

- Families matter - what are family's needs and how do we, the wider community support them?
- Schools matter - we have focussed on learning in schools, they are also social communities teaching children the values and expectations of their culture
- Communities matter - reflected in social attitudes to disability, beliefs about disability, services, financial support
- Children's competencies matter - social competence is learned within these social worlds and it is influenced by abilities, temperament and personality
- What knowledge do we have to guide us?

Research on family needs and strategies

- How do families cope?
- What can we learn from research?
- Families with children with Down syndrome usually show less stress than parents of other children similar levels of intellectual disability or with autism
- Research studies show that most families do well - they find the extra resources to cope with additional needs and lead ordinary lives
- Some families have a difficult time and need extra help
- We know what may make families vulnerable or help them to be resilient and cope successfully

Research findings - UK, Australia, USA

- Most families (70-75%) adapt, find the resources to cope and to lead ordinary family lives - they are resilient
- Marriage breakdown is no more frequent and may even be less frequent
- Brothers and sisters do not have more problems than in other families and are likely to be more caring
- Families report that there are extra demands - in meeting their child's additional needs but also in fighting for their rights and adequate service
- Most families report a range of benefits of having a child with Down syndrome - for the whole family

Research findings - UK, Australia, USA

- Resilient families tend to use practical coping strategies - they seek out information and services; they join parent support groups
- Resilient families develop a supportive emotional climate, are optimistic and encourage open communication between members
- Ageing parents of adults with Down syndrome tend to have better health and life satisfaction, and are more socially active than typical ageing parents
- Some factors enable families to deal with other life stresses like redundancy, bereavement, serious illness
Research findings – UK, Australia, USA

- Some families (25-30%) are vulnerable and experience considerable distress. In these families, everyone may be affected by practical, emotional and behavioural difficulties – the child with Down syndrome, parents and brothers and sisters
- Vulnerable families can usually be identified early and will benefit from specific support from relatives, parent support groups and professional services

Factors that make families vulnerable

- Family/parent factors
  - Poverty, poor housing, no car, unemployment
  - Poor marital relationships, family disharmony
  - Low self-esteem and self-confidence in parents
  - Passive, ineffective coping strategies – pessimism, not seeking and using resources and support
  - Poor relationship with child – lack of bonding (very rare 1-2%)
  - (same factors will put any family at risk and make parenting more difficult)

Factors that make families vulnerable

- Child factors
- Difficult behaviour
- Persistent sleep difficulties
- More severe developmental delays
- A difficult temperament – restless, over-active, impulsive, controlling
- Chronic health problems
- Acute, life threatening health problems
- (again would be same for other children)

Factors that make families vulnerable

- Services and support factors
- Limited family and social support
- Inadequate health, education and social support services
- Financial burden – care needs and limiting family income
- Negative community and/or family attitudes
- Discrimination in legislation

Implications for families

These research findings can be used to enable families to
- Be optimistic about the future for their child and their family
- Evaluate their own strengths and weaknesses
- Use effective practical coping strategies – seek information, support groups and services
- Identify potential sources of additional stresses and seek solutions – particularly for behaviour, sleep and health difficulties

Family centred approach

- Families need information
- Emotional support and understanding
- Services from the time of diagnosis – provided by informed and positive professionals
- Services need to put families first – provide the support that families actually want – that fits in with their views of their family life and their future
- Services need to be co-ordinated – keyworker approach
- Families need to be listened to and they should not have to fight for their rights
- They should not have to be the most informed person on Down syndrome in their support team!
**Early Support Approach**

- Early Support is now embedded into service provision by government (DCSF) – a requirement not an option
- See [http://www.earlysupport.org.uk](http://www.earlysupport.org.uk/) for all the materials, philosophy and practical guidance
- DSE led the development of the materials for families with children with Down syndrome
- Information book on Down syndrome and Developmental Journal to record and celebrate progress
- Free to families and practitioners in England
- Online so accessible

**Individual families**

- Remember that, despite the additional demands of a child with special needs – most families are fine
- But – keep a balance – every member of the family is equally important
- At times any member may need more attention due to illness or particular issues but child with special needs should not always be centre stage and take up more time
- Make use of respite from family or services to give other children time or have a break for husband/wife time

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**Remember the benefits**

- In parent surveys – families list the benefits while also listing the demands and worries
- Parents usually worry they have not had as much time for other children – yet the evidence says brothers and sisters usually fine
- Benefit from growing up and learning to understand and care for a child with Down syndrome
- Often go into caring professions, become child’s best advocate
- Parents also stress they have changed values, made friends and engaged in groups – found they had skills they did not know they had

**Individual families – keep a balance**

- Remember that being the much loved member of a happy family is the most important experience for a child with Down syndrome
- Doing ordinary things – going everywhere, being included
- So it is very important to focus on that and not let the extra demands distort family life for everyone
- If the choice is going to the park with neighbours and children or a lesson – go to the park
- And – while it is parents who have and are changing services and fighting for rights – do not do this to the detriment of your family and yourself

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**References**

- Teenage survey references

**Resources – Dsii series of books and videos**

- Both in Dsii Development and Education series
- A series on Adult issues is also available – edited by Roy Brown – and with an international team of authors
- All provide reviews of available research and guidance on evidence based practice.
- Available now by mail order from Trust see [www.dsiinternational.org](http://www.dsiinternational.org)
- Online versions and some translations available
Supporting social development and behaviour – early years

Overview

1. Social emotional development
2. Developing social skills
3. Learning to manage behaviour
   - prevention is better than cure
   - how to change difficult behaviour

What is social-emotional development?

• Social-emotional skills form the foundation for further development in other areas as they determine how cognitive, play and communication skills are acquired, used and developed
• They impact significantly on a child's ability to make use of learning opportunities in the environment

Social-emotional development

• The process of social-emotional interaction develops in a similar way in infants with and without Down syndrome
• The social-emotional abilities of children with Down syndrome are relatively unimpaired, despite delays in cognitive development

What is social-emotional development?

• Self-regulation – manage emotions
• Adaptability – copes with changes
• Reactivity – respond to events and demands
• Frustration tolerance – perseveres with tasks
• Expression of emotion
• Relationships with others
• Empathy
• Self-esteem
• Self-confidence
• Motivation

Developing social skills

• Encourage eye contact and babble games
• Follow child's lead in developing joint attention
• Join in games and read books to encourage concentration and increase attention span
• Be responsive to social interactions initiated by the child
• Provide opportunities to play with other children
• Provide opportunities to learn social behaviour from typically developing peers
• Provide a wide range of social experiences with family and friends
## Learning from others
- Increase awareness of emotional responses and eye contact
- Teach sharing, turn taking, waiting, offering/receiving
- Encourage social interest in others
- Teach vocabulary for emotions – from simple to complex
  - E.g. happy, sad, tired, hungry, angry, proud, scared
- Practise imitation games

## The importance of brothers, sisters and friends
- Relationships with other children play a very important role in social development
- Parents of more socially successful children tend to give them more play opportunities
- Ability to get along with same-age peers is relevant for child’s progress in pre-school and school, in taking part in social activities in their communities, and making their way in adult life
- All children learn from their brothers, sisters and peers

## Social opportunities
- Providing opportunities and support
  - Organising play areas so children can be near each other for play and communication
  - Duplicate set of toys for imitation
  - Encourage shared play and co-operation
  - Imitation is a great way to learn
  - Praising children for positive social behaviours

## Social development and behaviour
- The majority of children with Down syndrome have good social understanding and empathy
- They are quite capable of behaving in a socially appropriate manner if that is what is expected of them at home, at nursery and at school
- But they can also use this good understanding inappropriately – they know how to get a reaction
- For the family and in preschool we need chronologically age-appropriate behaviour expectations

## Getting it right from the start
- Children respond best when adults have high expectations, and provide appropriate support
- Easy to ‘baby’ children with Down syndrome
- Making allowances for unacceptable behaviour because a child has Down syndrome undermines the child’s potential to show the behaviour of which he or she is capable
- Positive messages about acceptable behaviour as early as possible

## Prevention is better than cure
- A key to promoting positive social behaviour is taking a proactive approach
- Settled, predictable daily routines from infancy
- Provide clear boundaries at all times
- Actively teach positive social behaviours, self-regulation and ways to express emotions
- Reward positive behaviours throughout the day
- Expect and reward age-appropriate behaviour right from the start
Prevention is better than cure

In home, preschool and school
- 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 cooperation and independence
- Provide ways of making choices and having some control
- Be aware of pressure on the child

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

Choose your battles wisely!!!!

Understanding difficult behaviours

- Always consider and investigate health issues before implementing a behavioural intervention:
  - Sleep
  - Diet
  - Sensory (vision, hearing, touch etc)
  - Teeth
  - Infections
  - Pain

The ABC of behaviour

<table>
<thead>
<tr>
<th>cue</th>
<th>Behaviour</th>
<th>consequence reward result reinforcer</th>
</tr>
</thead>
<tbody>
<tr>
<td>signal trigger stimulus</td>
<td></td>
<td></td>
</tr>
<tr>
<td>conditioning bridge</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Changing difficult behaviours

- Difficult behaviours can be changed by changing either the antecedents which lead to the behaviour, or the consequences that follow it
- Choose one behaviour to address at a time
- Always give child an appropriate alternative to the behaviour
- Adult behaviour must change if you want the child’s behaviour to change
- Everyone concerned with the child must agree to act in a consistent manner or behaviour will not change
- Time spent on planning is essential and must involve everyone in contact with child

General strategies for responding to difficult behaviours

- Many behaviours are repeated for the reaction or reward obtained
- 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
General strategies for responding to difficult behaviours

- Consistent responses and consequences
- Always consider consequences from child’s perspective
- Provide opportunities for positive attention and praise as soon as possible
- Social stories – keep to positive language
- Clear visual communication systems

What to expect...

- Behaviours that are allowed to persist become habits
- Worse before it gets better
- The longer a behaviour has been in place, the longer it may take to change
- Be consistent!
- Review plan regularly and make adjustments when necessary

Summary

- Social understanding, empathy and social interactiveness are areas of strength from infancy through to adult life
- Social behaviour is influenced by the same factors as it is for other children, their temperament and personality, language and cognitive abilities, emotional relationships, family environment, expectations and parenting styles
- There is a wide range of individual differences and the more developmentally delayed children are the most vulnerable
- It is important that parents and professionals have good management strategies in place and expect age-appropriate behaviour

5 case studies and interventions

Strategies to address challenging behaviour in young children with Down syndrome by Kathleen Feeley and Emily Jones
- Challenging behaviour linked with poor sleep
- Noncompliance – refusals
- Inappropriate hugging
- Avoidance
- Self-stimulatory behaviours
Freely available on Down Syndrome Online

Recommended reading

- Down Syndrome Issues and Information: education series
  - Social development for individuals with Down syndrome – an overview
  - An overview of the development of infants with down syndrome (0-5 years)
  - http://www.dseinternational.org/collections/books/social-skills
- Down Syndrome Research and Practice
  - The power of behavioural approaches – we need a revival.
  - http://www.dseinternational.org/updates/2010/12/2
  - S. Buckley
  - Strategies to address challenging behaviour in young children with Down syndrome. By Kathleen Feeley and Emily Jones

Recommended resources

- Down Syndrome online http://www.dseinternational.org/
- Right to Know CD 2004 – Down Syndrome Society of South Australia
- SEAL resources: archive of photos
  - http://nationalstrategies.standards.dcsf.gov.uk/node/891473
- How do I feel? By Joan Green. DSE online shop
  - http://store.greenenterprise.org/collections/books/products/how-do-i-feel