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Developing evidence based early intervention and education

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Some background

- Clinical psychologist by original training – worked in institutions
- Moved to community
- Started early intervention services in 1973
  - Very little information to guide us
- Began research in 1980 – language and reading
  - Conventional wisdom – not able to read with comprehension or count – effort will just lead to stress (David Gibson Down's syndrome 1979)
- Began inclusive schooling in 1988 – outcome research 1999
- Began memory research 1990
- What have we learned?

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My questions in the 1970s

- If a baby has Down syndrome they will have 'mental handicap' – this is a description based on delayed milestones not an explanation
- Why do they progress more slowly?
- What is different about the way they are perceiving and interacting with their world?
- Development takes place over time for all children – influenced by their genes AND their social and learning environments
- It is not fixed at birth
- What have we learned about child and environmental factors?
- **Need to address both**

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Our approach – 'why are we always right?'

1. Understand how Down syndrome has influenced children's learning
2. Always draw on research into typical development – what do we know about the processes? – delayed rather than different
3. Trace back to early years

- For example – research with teenagers highlighted verbal short term memory delay (VSTM) (e.g. Marcell et al., Hulme et al.,1980s)
- How does VSTM develop from first weeks of life? uses a speech code – a phonological system which babies learn from first weeks of life for their own language, is influenced by ability to discriminate and produce speech sounds, influenced by phonological awareness, by vocabulary learning – some pointers here for interventions all ages

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The importance of language

- My earliest concerns were how to develop our children's language?
- Why?
- Words for communicating needs, emotions,
- Words for friendship's and social relationships
- Words for knowledge – vocabulary size = knowledge
- Words for thinking, remembering, planning, problem solving – executive function – internal speech
- Words for managing behaviour – self regulation

Words are the building blocks of mental development

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Speech and language profile (1980s and 1990s)

- Spoken language tends to be delayed relative to non verbal mental abilities – we could see children understood more than they could say
- Verbal short term memory delayed relative to NVMA
- SLI pattern – Robin Chapman, Jon Miller Wisconsin
- Uneven profile within language domains
  - Communication and Vocabulary relative strengths
  - Grammar for sentences and clear Speech Production more challenges
  - Domains influence each other
- Risk of hearing impairment becoming known
- Observed benefits of teaching signs as a bridge to talking

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Speech matters

- We began to realise early that speech development matters
- Signs can be used to communicate – do not teach children speech sounds or phonology
- Pat Le Prevost SLT – realised benefits of signs in 1980s but soon realised she needed to work on speech as well
- Her first 'Sound Cards' and then Barbara Dodd's 'Core Vocabulary' programme led to our See and Learn Speech programme
- TD babies can discriminate speech sounds at 4-6 weeks, the sounds they can make at 8-10 months predict first spoken words (Stoel-Gammon 2011)
- The sounds they make influence VSTM development at 11 to 26 months (Keren Portnoy, Vihman 2010 The role of vocal practice in constructing phonological working memory)

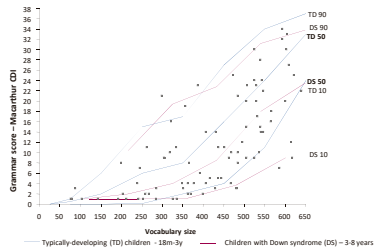
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Vocabulary matters - grammar link

- Vocabulary size is linked to grammar development
- Children with Down syndrome have a vocabulary delay
- 200-250 spoken words are needed before grammar starts
- Now this vocabulary grammar link reported for children with Down syndrome in English, Italian and Spanish (see Vicari et al. 2000, Zampini & D'Odorico 2011, Galeote et al 2013)
- **There will be many children with Down syndrome in kindergarten and primary/elementary schools who do not yet have 250 words in spontaneous spoken language**
- (e.g. from our data 33 children at age 60-71mths, mean number of spoken words =293.7 (SD183.4) **range 8-649 words** Pennanen 2000)

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



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Vocabulary matters

- Presented at a Newcastle conference: Dad said *"OK – I believe you so what are the first 400 words I should teach my child?"*
- DSE Vocabulary Checklists – to 800 words – developmental order based on MacArthur Communicative Development Inventories
- Already using a behavioural approach to teach first vocabulary – match, select, name pictures - now See and Learn Language and Reading
- Importance of visual supports, small steps, daily practice
- **Intensity matters:** Recent vocabulary intervention study 18-27 month olds with Down syndrome 5 daily sessions each week better than 1 session (Yoder 2014, 2015)
- **Speech matters:** increased use of voice (canonical syllables) by child predicted progress - increased parental linguistic mapping

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Memory matters

- We began memory training studies in the early 1990's to see if training might make a difference – trained rehearsal.
- Suggesting rehearsal training in a 2006 article Sue Gathercole, leading expert on child memory, says

'*groups with Down syndrome have been shown to benefit from training of an overt cumulative rehearsal strategy, in which participants are required to rehearse aloud increasing amounts of material in the course of a short-term memory task (Broadley & MacDonald, 1993; Comblain,1996; Laws, McDonald, & Buckley, 1996)*'.

- Since then Fran Conners et al (2008) in the US has shown positive effects of training parents to deliver rehearsal training.

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Memory training

- In 2013 with Sue Gathercole's group we tried computerised memory training – and showed 7 to 12 year olds could do the training - gains on visual spatial memory and lasted 4 months after training
- Joni Holmes, Sue Gathercole (2015, 2014) have shown that it helps children 8-11 years with low language or low achieving – gains in maths and English over 12 months
- Therezina Nunes, Barros (2014) in Oxford have shown that training improves working memory in deaf children – some computer based
- Parks et al (2014) 7-9 year olds - Phonological awareness training improves WM in children with SLI (20 mins daily for 4 weeks)
- Phonological awareness in schools – learning letter sounds, first sounds in words – may improve speech and verbal short term memory

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Importance of reading – starting early

- Took off with an early intervention and reading study 1980-1983
- Prompted by a father's observations – Leslie Duffen – Sarah remembered printed words from 3 years, it had developed her spoken language
- She remembered words and sentences read (seen and heard) better than when just heard
- We demonstrated he was right – reading sight words from 3 years or earlier – and deliberately used them to teach spoken language
- First study funded by DSA, next by Joseph Rowntree Fund (Chris Kiernan, Hester Adrian Centre – watched videos listened to me saying we needed many more years to evaluate – *'we will fund if you make a video and start sharing or another generations will be denied the chance to learn to read'*

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Reading matters

- When we published case studies and video in 1983 – I received hate mail – *"how dare I suggest anyone with Down syndrome could learn to read"*
- Group studies only became possible in 1990s as we had children in inclusive classrooms being taught to read – longitudinal study – matched with slow readers! (Byrne et al 2002)
- First RCT of a reading and language intervention 2009-2012 with world experts Charles Hulme, Maggie Snowling (£500,000 grant)
- A balanced approach – sight words, letter sounds, phonics in the context of successful book reading from the outset
- Adapted to address the 'Down syndrome profile' – language delay, small steps, structure, VSTM, visual supports, attention
- And designed to be individualised for every child – not 'one size fits all'

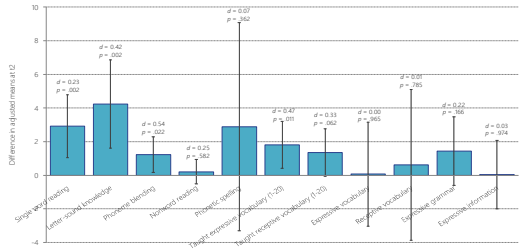
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Reading matters – RLI study Burgoyne et al 2012

- 57 children, all abilities, fully included, 50 schools took part
- TAs taught to deliver daily intervention sessions – 'easy' to roll out
- Significant gains on letter knowledge, word reading, phoneme blending, expressive vocabulary – compared to waiting control group
- These reflect directly taught skills – and these gains did not yet transfer to gains in spelling, non word reading or standardised language measures. Maybe not a surprise given the demands of the reading tasks and the extent of language difficulties for children with Down syndrome
- The waiting control group progressed faster when they moved to the intervention – and showed similar gains to the intervention group

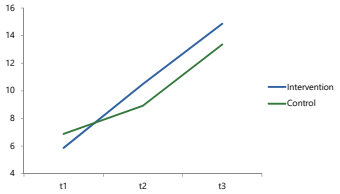
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Effect of Intervention: Week 20 – RCT findings



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Word Reading – assessment data RLI



- Wide variation in reading progress – (range raw score gains 0-36 over 40 weeks)
- 21 children unable to score at t1; 5 at t3
- 10 children achieved age-appropriate word reading at t3

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Individual differences in progress

- Wide variation in progress made on intervention – some children made rapid progress, others slower progress
- What influenced progress? **age, receptive language and intensity of teaching**
  - Younger children tended to make more progress – those **starting at 5 and 6** years – learning with everyone else in the class
  - Children with better receptive language tended to make more progress
  - Children receiving at least 80% of the intervention sessions made more progress – teaching matters and **progress takes time** (Allor et al 2014)
- **Children with Down syndrome are ready to read at 5-6 years in school – and from 3 years** (Colozzo et al 2016)

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Research to practice – reading is a strength

- A number of studies have shown that children with Down syndrome often have reading ages ahead of language ages and mental ages (e.g. Hulme et al 2012) - reading is a strength and should be developed
- Wide range of outcomes but books for all – supported reading
- RLI roll out - Handbook, video presentation, training, online training, Facebook support …. Accredited RLI trainers in UK and USA
- Handbooks to date - 2,270 copies in 37 countries (1000+staff reached)
- We have school districts in the UK, US and elsewhere implementing RLI with all children with cognitive and language delays once they saw how it helped children with Down syndrome
- Experienced special ed teacher -*"he has made more progress in last 4 weeks than last school year"* – specific targets, small steps, structure

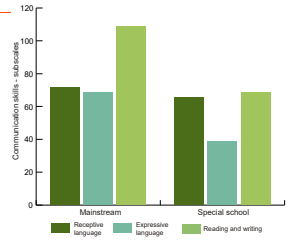
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Evidence that school environments matter

- A number of studies show that when children with Down syndrome are fully included in mainstream/regular education settings they develop better spoken language and reading (see de Graaf et al review 2012) – also make progress for longer through teenage years
- You may be familiar with our own work in the UK illustrated on the next slide (Buckley et al 2002, 2006)
- Recently supported by larger studies in the Netherlands by Gert de Graaf and colleagues – who show children with IQs below 50 in mainstream settings do better than those with IQs above 50 in special education settings (de Graaf et al 2016)
- Why? Richer language environment, wider curriculum, literacy, more time on academics, better teaching, peer group?

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Language and literacy -inclusion study

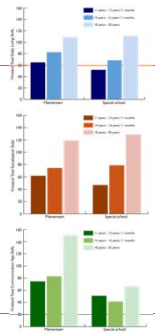


Vineland Adaptive Behaviour Scale – age equivalent scores

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

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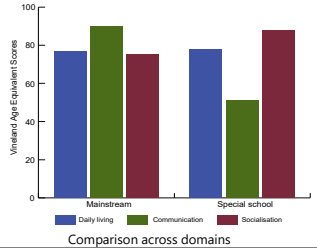
Progress with age



- 11-13;11 years
- 14-16;11 years
- 17- 20 years
- Still progressing - no evidence of plateaux
- But little language progress in special school settings
- NB cross sectional data

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Closing the speech-language/non-verbal ability gap



Comparison across domains

The included children

- are in a much richer spoken language world
- access a wider curriculum
- receive more literacy instruction
- have a much higher involvement in supported literacy as they are in all lessons
- had teaching adapted to their learning profile

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Changing 'the Down syndrome profile'

- On the last slide we used the Vineland Adaptive Behaviour Scales
- Using this measure Dykens, Hodapp 1994 first drew attention to this profile in children with Down syndrome 1-11 years and Debbie Fidler and colleagues showed it is emerging in 2-3 year olds
- We see this profile in our data only for children being educated in special school environments
- We looked at individual differences 73% in special ed. showed the expected profile compared to 17% in the inclusive education group
- Danger of 'profile' seen as fixed or inevitable result of Down syndrome
- **Reminder: children's (and teen's and adult's) development is influenced by their opportunities to learn – including those with Down syndrome**

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Language environments at home and school

- Couple of recent studies show the risk that parents may talk less to their children with Down syndrome because they are not talking (Thieman-Bourque et al 2014, Parikh, Mastergeorge 2017)
- 'It takes two to talk'
- Large differences in rates of language learning – all children
- Recent paper on conversational turns – 4-6 year olds - TD children who experienced more conversational turns with adults showed more activation of Broca's area when story listening. Conversational experience impacts neural language processing over and above SES, IQ.
- Food for thought for parents and teachers

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Priorities in early intervention and education

Addressing child issues:

- Speech and language development – a curriculum priority from birth to adult life (and always assess/compensate for hearing loss)
- Speech discrimination, speech production – all ages
- Teach vocabulary and grammar – all ages
- Support VSTM – 'make it visual', signing, pictures, print, computers, apps + memory training – all ages
- Teach reading – it will support grammar learning – all ages

Teaching approach:

- Precise teaching targets, small steps, structure, intensity
- Have patience, keep teaching – progress takes time continues to adult life

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Inclusion in school and community

Addressing environmental issues – maximising learning opportunities:

- Improve quantity and quality of language input at home and school
- Children learn from other children - full inclusion in nursery, day care, preschool and school
- Full member of the class – 'I belong' (not a visitor)
- Inclusive education – much evidence of benefits for our children
- Needs to be done well – high expectations, behaviour support
- Inclusive schools best for everyone – Swift Centre, Kansas, Lani Florian Edinburgh and many others best practice guidance – more than 20% of children have additional needs
- We ALL need to fight for change – segregation on the basis of disability is not acceptable

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Acknowledgments

- All the children, young people and families from whom we have learned so much
- All the practitioners we have worked with in schools and services from whom we have learned so much
- All the students and colleagues who have been involved in our research studies, our training, publications, early intervention and school support services
- Some are here, Rebecca Baxter, Kelly Burgoyne and Gillian Bird so do make contact with them
- All our funders over the years

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Meet the plenary speaker session

- Thursday 11:30 Morar – with Isla Ross and Debbie Fidler
- E mail me for further information, handout and references sue.buckley@dseinternational.org
- I can provide bespoke online training and consultancy
- Go to our website https://www.down-syndrome.org/
- See and Learn https://www.seeandlearn.org/en-gb/
- RLI https://www.down-syndrome.org/en-gb/resources/teaching/rli/
- Free online video presentations https://www.down-syndrome.org/en-us/presentations/
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Roberta's life , 48, full social inclusion possible for all

Very limited education – missed out until 21 – but very full adult life

Supported living, friends, work, social life, love, partners



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