Is the Irish model for resource allocation failing children with Down syndrome?

- Down syndrome is a complex developmental disability which includes physical and intellectual disabilities
- Down syndrome results in a specific behavioural profile with implications for the delivery of effective education
- Most (84%) of school age children with Down syndrome have IQs 50 or below and all have language and memory deficits that are below their IQ expectations
- Children with Down syndrome enter school with very delayed language (language ages of 2-3 years, limited unclear speech) and significant working memory deficits.
- Working memory (WM) deficits will affect all learning and WM predicts academic progress better than IQ.

- Children with Down syndrome have visual and hearing impairments, motor and social delays
- They make up 0.2% of the child population
- Their complex profile of disabilities should clearly qualify them for 'low incidence' resource teacher support
- Children with Down syndrome have better academic outcomes in mainstream – provided they are supported adequately with teachers and assistants trained in how to meet their needs
- Denying them 'low incidence' levels of support means they do not have the level of support they and their teachers need to succeed
What is Down syndrome?

- Down syndrome is caused by the presence of an extra copy of chromosome 21 from the time of conception
- It occurs in approximately 1 in 600 live births in all communities (about 1 in 1000 where termination is legal)
- The only known risk factor is age – risk increases as mother’s age increases
- Down syndrome effects all aspects of a child’s development – both physical and mental development
- It is a complex developmental disability and in recent years a specific behavioural phenotype has been described refs 1-4

How does Down syndrome effect development?

- Down syndrome affects all areas of development
- All areas of development - social, motor, cognitive, speech and language – are delayed for chronological age
- BUT all areas are not effected to the same extent – we see an uneven profile of strengths and weaknesses when we take non-verbal mental age as our baseline.
- This leads to what is described as the behavioural phenotype illustrated in a diagrammatic form on the next slide
- The educational implications of this phenotype have been documented and continue to be explored

An overview of the behavioural phenotype associated with Down syndrome
Main educational implications

<table>
<thead>
<tr>
<th>Hearing and vision impairments</th>
<th>Impairs access to classroom instruction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intellectual disability – IQ decreases during childhood</td>
<td>Slower to learn and limits understanding</td>
</tr>
<tr>
<td>Specific speech and language delay</td>
<td>Limited understanding and communication</td>
</tr>
<tr>
<td>Specific verbal short-term &amp; working memory delay</td>
<td>Severely limits attention, processing and learning</td>
</tr>
<tr>
<td>Delayed motor skills – fine and gross motor control</td>
<td>Delays handwriting, limits self-help, play and sport</td>
</tr>
<tr>
<td>Delayed social development and behavioural control</td>
<td>Immature behaviour and behaviour challenges</td>
</tr>
</tbody>
</table>

Cognitive delay – intellectual disability

IQ of children with Down syndrome

- Age 1 year have mean IQ of 75
- Age 2 years have mean IQ of 67
- Age 5 years have mean IQ of 59
- Age 9 years have mean IQ of 40 (84% IQ 50 or below)

Why this decline? – because IQ is always a comparison with same age ‘typically developing’ peers
- If you do progress each year but at a slower rate than TD children your mental age will increase but your IQ will drop – classroom support needs will increase

Most school age children with Down syndrome have IQs below 50

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 delay

Children with Down syndrome enter school with very delayed language (language ages of 2–3 years, limited unclear speech)

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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.
- Working memory (WM) deficits will affect all learning and WM predicts academic progress better than IQ. Ref 9 WM deficits are severe for children with Down syndrome.

The benefits of inclusive education – full details ref 10.

- Very significant gains in literacy (mean gain 3.3yrs) and expressive language (mean gain 2.5yrs) 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

Experience of inclusive education

- The evidence shows that children with Down syndrome have better academic outcomes when educated in mainstream classrooms ref 10-13
- This will only be the outcome if they are allocated sufficient classroom and teacher support
- One-to-one support is needed to plan teaching and support learning if they are to reach their potential in literacy and numeracy
- Class teachers need the support of a resource teacher experienced in teaching children with Down syndrome
- One-to-one assistant support is needed to facilitate social inclusion and prevent behaviour challenges
NCSE report – principles

- Principle 1: All children, irrespective of special educational need, are welcome and able to enrol in their local schools.
- Principle 3: All students with special educational needs have access to available educational supports in line with their needs.
- Principle 4: Students with special educational needs have an individualised assessment which informs teaching and learning and forms one part of an ongoing and cyclical process of assessment, intervention and review of outcomes.

Department of Education Circular SP ED 02/05

<table>
<thead>
<tr>
<th>Learner Incidence Disabilities</th>
<th>Hours of resource teaching support available per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Disability</td>
<td>3</td>
</tr>
<tr>
<td>Hearing Impairment</td>
<td>3</td>
</tr>
<tr>
<td>Visual Impairment</td>
<td>3</td>
</tr>
<tr>
<td>Emotional Disturbance</td>
<td>3</td>
</tr>
<tr>
<td>Specific Learning Disability</td>
<td>3</td>
</tr>
<tr>
<td>Moderate General Learning Disability</td>
<td>3</td>
</tr>
<tr>
<td>Severe / Profound General Learning Disability</td>
<td>5</td>
</tr>
<tr>
<td>Autism Spectrum Disorder (ASD)</td>
<td>5</td>
</tr>
<tr>
<td>Specific Speech and Language Disorder (Speech and Language Disability)</td>
<td>5</td>
</tr>
<tr>
<td>Severe / Profound General Learning Disability in combination with one of the above learner incidence disabilities</td>
<td>3 to 5, taking into account the pupil’s special educational needs including level of general learning disability</td>
</tr>
<tr>
<td>Multiple Disabilities</td>
<td>5</td>
</tr>
</tbody>
</table>

Children with Down syndrome

- Children with Down syndrome should qualify for low incidence support regardless of IQ
- Most (over 80%) will have IQs in the moderate range (below IQ 50) in school years
- Most (80%) will have some degree of hearing and visual impairment
- All will have significant working memory, speech and language delays and difficulties more severe than would be predicted by their non-verbal IQ
- All are at risk of developing difficult behaviour if not adequately supported
The bottom line – the rules do not work

• Why are they excluded when they are ‘low incidence’ less that 0.2% of population?
• Why are they excluded from resource teaching when their level of need is clearly as great or greater than that of conditions which do qualify?
• The Irish education resource allocation rules are failing children with Down syndrome
• Experience indicates that children with Down syndrome will fail and be moved to special school if not supported by teachers and assistants experienced and trained in their specific learning profile

Successful primary and secondary inclusion

References - specific phenotype and IQ

3. Down Syndrome Research and Practice 9 (3) section on the specific behavioural profile - three papers Hodapp et al, Fidler et al. and Buckley et al. free online at http://www.down-syndrome.org/research-practice/
References – IQ, speech, language and memory


Benefits of inclusion – indicative references


Further information

DVD Inclusion in practice – educating children with Down syndrome at primary school http://store.dseenterprises.org/

Professor Sue Buckley OBE
Director of Research
Down Syndrome Education International
Emeritus Professor of Developmental Disability
University of Portsmouth UK
Email sue.buckley@dseinternational.org
Website www.dseinternational.org