Children with Down Syndrome Attending Mainstream Schools

Background

Down syndrome is a chromosomal anomaly caused by the presence of all or part of an extra 21st chromosome. It is a complex, low incidence disorder. Between 1 in 319 and 1 in 1000 live births worldwide are trisomic for Hsa21 (Wiseman et al, 2009) Occurrence in Ireland is likely to be at the higher end of this. (1:546, DSMIG, 2001).

Down syndrome is associated with abnormalities in multiple organ systems and a characteristic phenotype that includes numerous behavioural features. (Abbeduto et al, 2007, Wiseman et al, 2009). There is considerable individual variation in how Down syndrome manifests, however there are also a number of common features. These include:

- intellectual disability,
- cranio-facial anomalies,
- language impairment,
- hypotonia (low muscle tone) and
- increased incidence of various medical and sensory issues, including hearing, vision, heart and thyroid disorders. (Bull et al, 2011; DSMIG)

Research has shown that children with Down syndrome gain academic, social and behavioural advantages from being educated with their typically developing peers in mainstream schools (Buckley et al, 2006). The nature of the disabilities and the differences in learning styles directly attributable to Down syndrome mean that additional teaching resources are needed in order to support learning and promote equality of opportunity.
Mainstream schools in Ireland have three main ways of supporting children with disabilities:

- special needs assistants (SNAs),
- learning support through the General Allocation Model (GAM), and
- allocated resource teaching.

The provision of these supports for children with Down syndrome is discussed below.

**Special Needs Assistants**

SNAs are provided if an educational psychologist report indicates that a child has 'care' needs in excess of those experienced by other children. Children who need support with toileting, walking upstairs, following instructions, etc. may qualify for an SNA.

SNAs are not trained teachers and their role is not to support the child’s academic work, but rather to ensure the safety and well-being of the child in school, and to support the child’s access to the curriculum.

**Learning Support Teaching**

Each school is allocated a number of teaching hours for learning support. The number of teaching hours allocated to a school is based on the number of children enrolled in the school. This is a social, rather than a medical model of provision. It is based on a number of assumptions:

- There will always be a number of children who struggle with educational achievements for various reasons; (e.g. mild learning disability, mild social or emotional difficulty, mild dyslexia, mild hearing or visual difficulties);
- The percentage of children who fall into this category of 'high incidence disabilities' is fairly predictable;
- The best way of helping these children is not through a lengthy medical or psychological assessment process, but rather additional teaching in the areas they have difficulty;
• Schools can be trusted to support these children if given a general allocation for extra teachers to do so
• These kinds of educational difficulties are more common in areas where the socio-economic environment is poor, so schools in areas of deprivation need an increased allocation;
• Additional resources are required for children with more complex, multifaceted disorders.

**Resource Teaching**

Resource hours are extra teaching hours by a qualified teacher, funded by the Department of Education for the benefit of a specific child with needs greater than those catered for by the GAM.

In contrast to the learning support teaching described above, resource teaching is allocated on a medical rather than a social model (i.e. it is disability based, rather than needs based).

In order to be allocated resource teaching hours, a child must meet certain strict medical or educational criteria. (See below, from Department of Education Circular SP ED 02/05).

For every child a school enrolls with one of the “low incidence” disabilities outlined below, the Department of Education will allocate the school a number of extra teaching hours for that child. (These hours have been reduced in recent cutbacks, but the principle still stands)

<table>
<thead>
<tr>
<th>Low Incidence Disabilities</th>
<th>Hours of resource teaching support available to school per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disability</td>
<td>Score</td>
</tr>
<tr>
<td>----------------------------------------------------------------</td>
<td>-------</td>
</tr>
<tr>
<td>Physical Disability</td>
<td>3</td>
</tr>
<tr>
<td>Hearing Impairment</td>
<td>4</td>
</tr>
<tr>
<td>Visual Impairment</td>
<td>3.5</td>
</tr>
<tr>
<td>Emotional Disturbance</td>
<td>3.5</td>
</tr>
<tr>
<td>Severe Emotional Disturbance</td>
<td>5</td>
</tr>
<tr>
<td>Moderate General Learning Disability</td>
<td>3.5</td>
</tr>
<tr>
<td>Severe / Profound General Learning Disability</td>
<td>5</td>
</tr>
<tr>
<td>Autism / Autistic Spectrum Disorders (ASD)</td>
<td>5</td>
</tr>
<tr>
<td>Specific Speech and Language Disorder (child’s IQ must be normal or higher to qualify)</td>
<td>4</td>
</tr>
<tr>
<td>Assessed syndrome in conjunction with one of the above low incidence disabilities</td>
<td>3 to 5, taking account of 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 who have a mild intellectual disability fall outside these criteria as currently applied. As a result of this, schools that have enrolled children with Down syndrome who have an IQ in the mild range are not allocated any additional teaching hours for that child. Any extra teaching the child needs must come out of the GAM.

This is problematic both for the child with Down syndrome and for other children in the school who have high incidence disabilities. Resources intended for the support of these children are now also being used to support children with Down syndrome who have complex, global disabilities.

**Discussion**

Currently, children with Down syndrome who have IQ scores falling in the mild range of intellectual disability are given learning support under the GAM. In the recent review of the GAM, questions were raised regarding children with Down syndrome.
Specifically, it was questioned whether children with Down syndrome who fall into the mild ID category should be included in the GAM along with high incidence disorders, or, whether there are sufficient grounds to consider Down syndrome as a low incidence disorder warranting specific allocation of resources. (*Recommendation 11: It is recommended that research is undertaken to establish if there is a sound and equitable basis for re-classifying Down syndrome as a low incidence disability. Review of the primary school general allocation model, DES, Dec 2012*)

Down syndrome is a disorder which affects around 1 child in 546 in Ireland (DSMIG). This means that incidence of Down syndrome is considerably lower than some of the ‘low incidence’ disorders in the table above. For example, the current incidence of Autistic Spectrum Disorders is estimated to be 1.1%, or just over 1 in 100 children in Ireland (HSE, 2012). Yet Autistic Spectrum Disorders are recognised as low incidence, but Down syndrome is not.

Down syndrome is a complex condition associated with abnormalities in multiple organ systems (see additional disabilities section below).

Down syndrome is one of the leading causes worldwide of Global Developmental Delay. Global delay can be defined as significant delay in two or more developmental domains:

- gross and fine motor;
- speech and language;
- cognition;
- personal and social development;
- activities of daily living.

Significant is defined as performance which is two or more standard deviations below the mean on developmental screening or assessment tests. (McDonald et al, 2006).

The majority of children with Down syndrome have significantly delayed development in all of the areas above.

All children with Down syndrome have significant delay in at least three areas, as the syndrome invariably affects muscle tone, and hence motor development; intellectual ability, and hence cognitive development; and speech and language development.
This indicates that Down syndrome is a complex disorder which has many facets, not merely a cause of cognitive disability, and as such, should be added to the list above.

**Additional disabilities faced by children with Down syndrome**

As seen in the definition above, Down syndrome is a chromosomal disorder affecting multiple organ systems, and causing global developmental delay. Some of these disabilities are major and pervasive. Others can be milder, but the cumulative effect of multiple disabilities is a difficulty in accessing the curriculum and learning without additional teaching resources.

Some of the specific disabilities faced by children with Down syndrome are outlined below:

- **Hearing**

  89% of children with Down syndrome have some form of hearing impairment (Bull et al, 2011). Even a minor hearing impairment (thresholds of 30-35 dB) means that around one third of speech sounds are sub-audible. This could rise to half or two thirds of speech sounds in a noisy classroom environment.

  Between 50 and 70% of children with Down syndrome suffer from fluctuating hearing loss caused by otitis media or glue ear (Bull et al, 2011). This means that hearing can be adequate one week, inadequate the next. Long intervals between hearing tests mean that these fluctuating problems are often overlooked, although they can have a significant impact on a child’s ability to access the curriculum.

- **Speech and language**

  As Down syndrome selectively impairs speech and language acquisition, all children with Down syndrome will have delays in these areas over and above what would be expected with a mild learning disability.

  Cleland et al (2010) found that individuals with Down syndrome present with deficits in receptive and expressive language that are *not wholly accounted for by their cognitive delay*. 
Martin et al (2009) also concluded that strong evidence suggests that phonology, expressive vocabulary, receptive and expressive syntax and some pragmatic aspects of language are impaired (in Down syndrome) beyond expectations for nonverbal cognitive level.

Speech and Language impairments affect access to all areas of the curriculum, not just language tasks.

- **Memory**

  **Auditory memory**

  Auditory memory and processing are also selectively impaired in children with Down syndrome. Laws (1998, 2004) found impaired phonological memory skills (memory for sounds and sequences of sounds) to be associated with poorer language comprehension, reduced mean length of utterance and reading difficulty in children and adolescents with Down syndrome.

  Frangou et al (1997) found that verbal processing deficits may be directly linked to atypical brain development, most notably a smaller planum temporal, and, as such, could be regarded as a primary phenotypic feature of Down syndrome.

  Wiseman et al (2009) found structural abnormalities in the brain (specifically in the hippocampus region) that are likely to contribute to deficits in learning and memory.

  Auditory processing and memory are important for all types of learning, not just specific memory related tasks.

  **Working memory**

  Working memory is a temporary storage system under attentional control that underpins our capacity for complex thought. (Henry, 2012)

  Children with Down syndrome show specific difficulty with phonological short term memory and episodic memory beyond what would be expected given their overall cognitive functioning. (Henry, 2012) The specific impairment in short-term memory for
verbal information will make processing verbal information and, therefore, learning from listening, especially difficult for children with Down syndrome. (Hughes, 2006)

Impairment in at least two of the main components of working memory mean that children with Down syndrome learn and remember skills and information in a different way to other children, and this needs to be taken into account in the classroom. Visuo-spatial working memory is relatively good, and so visuo-spatial information is likely to be conceptually easier, but children with Down syndrome also have major difficulties with visual acuity, as discussed below.

- **Vision**

Visual impairments (50% of children with Down syndrome wear glasses) may make it difficult to retain focus on written work. Usually, children focus very easily and very accurately on near targets and it is only as we approach middle age that we expect to experience difficulty in focusing at near.

Over 70% of children with Down syndrome focus very poorly at near. They tend to under-accommodate by quite a large amount (Woodhouse, 2005). This is often not adequately corrected by wearing glasses.

It is important for teachers to acknowledge that, even if children wear glasses (including bifocals) successfully, or if they focus accurately without glasses, their visual acuity will still be below normal. Thus reading materials, for example, do not look the same to a child with Down syndrome as they do to his/her classroom peers. The material does not appear to have the same level of detail. Enlarging the print may help the child to access print more easily, but does not restore a 'normal' appearance to the material (Woodhouse, 2005).

Woodhouse further recommends that all children with Down syndrome, whether they wear glasses or not, receive input from teachers for the visually impaired, to ensure that classroom materials are adequate.

- **Motor**
One of the primary phenotypical features of Down syndrome is hypotonia (Wiseman et al, 2009). Low muscle tone causes delays in gross and fine motor development.

Children with Down syndrome are likely to need both physiotherapy and occupational therapy support in order to participate in the classroom.

For example, it may be difficult to maintain posture while sitting in a chair, or to manipulate a pencil while maintaining sufficient pressure to write and draw.

- **Medical**

Down syndrome affects multiple organ systems, leading to increased incidence of many medical conditions. Some of the major conditions are outlined below.

- Sleep apnoea affects 30-60% of children with Down syndrome. (Bull, 2011) This can cause poor growth, further delayed development, as well as concentration and attention problems. (It's difficult to focus when you are exhausted)

- Cardiac issues occur in 40-60% of children with Down syndrome. (DSMIG) These can also affect growth, development, and concentration. (Exhaustion can arise from poor cardiac function, as well as poor sleep)

- Hypothyroidism occurs in between 4 and 16% (rising in adolescence)

- Childhood leukaemia is around 20 times more frequent in children with Down syndrome than in mainstream children (Bull, 2011)

- Auto immune diseases like coeliac disease and inflammatory arthropathy are all considerably more common than in the general population.(Bull, 2011)

Medical issues, which may not seem directly related to learning, are likely to lead to exhaustion and may increase vulnerability to minor infections. Absences due to minor infections and general exhaustion, along with frequent medical appointments (to monitor various conditions) lead to poorer school attendance than their peers, and hence fewer opportunities to learn.
Conclusions

Down syndrome is a complex, low incidence disorder. (See discussion above)

Children with Down syndrome in mainstream schools are poorly supported by the Department of Education at present.

Although allocation of resource teaching operates on a medical model, in practice, resource hours for children with Down syndrome are allocated purely on the basis of assessed IQ, rather than overall cognitive, medical and developmental profile.

Additional disabilities are not recognised, unless they are severe enough to meet the criteria set out as low incidence disabilities in their own right. This amounts to discrimination against children with Down syndrome.

Other children are allocated resources on the basis of having a low incidence, complex disability. Down syndrome is, by definition, a low incidence, complex disability which affects multiple areas of development, but children with Down syndrome have to prove a second complex low incidence disability which is on the list above in order to qualify for resources.

Further systemic discrimination is present in the fact that language disorders are only recognised by the DES in children who have an IQ of 90 or above. This effectively means that no child with Down syndrome is ever given resources on grounds of language disorder, despite the fact that language disorder (over and above what would be expected for cognitive ability) is one of the defining characteristics of Down syndrome.

The Education for Persons with Special Educational Needs Act 2004 (EPSEN), section 21 (g) states:

‘One of the functions of council (National Council for Special Education) is ‘to ensure that a continuum of special educational provision is available as required in relation to each type of disability’.

Children with Down syndrome have both Global developmental disorder and pervasive, developmental speech and language disorder for which there is currently no special educational provision.
Children with Down syndrome face considerable difficulties in being accepted and valued as members of an integrated society. Education policies which amount to institutionalised discrimination are adding to these difficulties.

Children with Down syndrome have the right to be educated in the least restrictive environment, and to be given appropriate supports to enable them to access the curriculum and learn effectively.

".. literacy and numeracy are among the most important life skills that our schools teach. Children should not leave school without having mastered these skills to the best of their abilities. Literacy and numeracy skills are crucial to a person’s ability to develop fully as an individual, to live a satisfying and rewarding life and to participate fully in our society. Ensuring that all young people acquire these skills is one of the greatest contributions that we can make to achieving social justice and equity in our country". (Ruairí Quinn, National strategy to improve literacy and numeracy, DES 2011)

Children with Down syndrome are currently not being given a reasonable, equitable allocation of resources to enable them to develop these skills. This situation needs to be urgently addressed. Down syndrome needs to be added to the list of complex, low incidence disorders that are recognised by the DES in order to enable additional teaching resources to be accessed by schools.
References:


DSMIG (Down syndrome medical interest group)UK and Ireland. Medical Management of Children and Adolescents with Down Syndrome in Ireland. 2001


National Review of Autism Services Past, Present and Way Forward, HSE 2012

National Strategy to Improve Literacy and Numeracy among Children and Young people: Literacy and Numeracy for Learning and Life. 2011 DES

Review of the primary school general allocation model. DES. 2012
