Educating a syndrome? Seeking a balance between identifying a learning profile and delivering inclusive education.

Education and health frequently operate within different paradigms. In the education system the delivery of service is generally to groups of individuals, whereas in the health system it is generally to the individual. The shift to the other's paradigm only occurs when something is going wrong. We look for wider social solutions (such as banning smoking) when we can't cope with the number of individuals with a health problem, and we look at identified learners when they disrupt our ability to teach the group. I am, of course, oversimplifying a complex series of relationships; but recognising this potential clash of worldview is important when we consider a child with a medical label within the education system.

Historically within the education system, when an individual has received a syndrome label it has been as a consequence of, or precursor to, their segregation. This segregation may be within a separate institution, building, room, or part of the room. It almost invariably involves a separatist state of mind. This is in fundamental conflict with the aims and ethos of inclusive education. How can we expect educational practitioners to treat individuals equitably if they are focussing on their codified differences and not on their relative position within the collective? It may seem as if this introduction is drifting off into rhetoric, but this question arises quite clearly from the research evidence available to us.

Starting with the teacher
In one of three systematic literature reviews recently carried out with colleagues (Rix & Hall, 2006)*,* we focused upon the nature of the interactions in pedagogical approaches with reported outcomes for the academic and social inclusion of pupils with special educational needs (SEN). A common theme across all the studies was the powerful role the teacher played in shaping interactions and influencing learning opportunities through those interactions. Detailed observational analysis combined with interviews, questionnaires diaries and curriculum assessment showed that when teachers had positive attitudes towards the inclusion of children with SEN, it was reflected in their interactional patterns and, in turn, in their pupils' self concept. Teachers who felt responsible for fostering the learning of all promoted higher order interaction; this was characterised by questions and statements involving problem-solving and reasoning. They supported fuller pupil participation, encouraging pupils to identify their thoughts and assisting them to document them. These teachers engaged in one-to-one discussion and frequently elicited prior knowledge and understanding, matching their questions and answers to the pupil's response, following the pupil's thinking rather than just checking that their understanding equated to the teacher's and implicating a point of view. This contrasted with teachers who saw the child as the responsibility of someone else. They had less successful outcomes and their interactions focused on procedural matters, behaviours and general classroom management.

Such findings across a range of learners with learning difficulties are echoed by research carried out in 18 schools in the UK and specifically framed around the Down syndrome label (Fox, Farell & Davis, 2003). They too found that the teacher had to be central to the whole support arrangement. They could not rely upon a teaching assistant (TA) to be the expert, working only with the identified child. All those working in the class had to be given time to share in the planning process but ultimately they needed to be accountable to the central figure of the teacher. The importance of this

was clearly highlighted by changing practice across years, involving the same children and support staff:

> "It was disappointing, therefore, to return the following year and observe a very different support arrangement. The new class teacher had organised the child so that he worked alone on his own personalised workstation away from his peers with a TA by his side. The planning was predominantly left to the TA and the class teacher had little idea as to his progress. He was not viewed by the other children in the same way as he had been the previous year since they were no longer used to interacting with him in class and did not include him so readily in their play." (pg 187, Fox, et al, 2004)

The negative response of peers is a key concern. Learning is a social activity and to be effective we need to feel that we are valued participants in the learning process (Rogoff, 1990). Peer group interactive approaches have been shown to be academically productive too. They have the capability to enhance social participation as well, and to positively influence children's attitudes to their learning, competence, acceptance and self-worth (Nind & Wearmouth, 2004). Such an approach is frequently in evidence. In a study on the inclusion of pupils identified as having Down syndrome, Scheepstra (1998) found that 20 out of 23 teachers used co-operative instruction. For this approach to be productive however, teachers need to recognise the importance of the social engagement of learners. They need to carefully plan group work, delineating the roles of group members, including activities in which social interaction is seen as the means to enhance the academic and social inclusion of the children (Sheehy & Rix, 2009).

Achieving social inclusion is perhaps the biggest challenge facing teachers. Social relationships and friendships with mainstream peers rarely move beyond the school (Cuckle & Wilson, 2002). For everyone within the school and class community, therefore, it is beneficial to frame difference as something experienced and created within day to day interactions with resources, activities and each other, rather than on the basis of criteria ordained externally (Alton-Lee, Rietveld, Klenner, Dalton, Diggins & Town, 2000).

Acknowledging external notions of difference
All of the above is well and good, but teachers frequently complain that they do not have the skills, experience or resources to effectively include children with SEN within the mainstream (Scruggs & Mastropieri, 1996; OFSTED, 2004). This is not that surprising; afterall Special Educational Needs, in most countries, are framed as needs which are additional to those provided to the majority. As a consequence, the teacher's lack of self belief is likely to create a self fulfilling prophecy.

All educational practitioners need to be convinced that they both can and ought to be including the child within the mainstream. The evidence available to language specialists is particularly useful in this context. In comparing the outcomes of 46 students at secondary level in mainstream and segregated provision, the average gain for the expressive language of the mainstream students was 2 years and 6 months and 3 years and 4 months for literacy (Buckley, Bird, Sacks & Archer, 2006). A comparison of 44 children in primary and secondary special and mainstream provision found that vocabulary development was on average 18 months in advance, and grammatical comprehension 9 months, with more rapid advances in the primary years (Laws, Byrne & Buckley, 2000). Similar positive outcomes can be demonstrated in relation to reading when compared to typically developing peers. In comparing the progress of two same-age groups of 18 children across three years, by the age of around 7, 94% of the typically developing children and 61% of the children supported as a result of their Down syndrome label were achieving equivalent standardized test scores in reading and reading comprehension (Appleton, Buckley & MacDonald, 2002).

Teachers may also feel better prepared if they have access to a learning profile, which outlines the typical characteristics of the syndrome. When considering such factors, they need be aware that a syndrome is a conglomeration of possibles. The possibles for children recognised as having Down syndrome suggest that speech and language will develop much more slowly than their non-verbal abilities would predict. They will tend to understand sentences of significantly more complexity than they can speak, and whilst vocabulary will be learned slowly and steadily throughout childhood, grammar will pose a potential lifelong challenge, as will speech intelligibility. The research evidence base exploring these observed characteristics comes mainly from experimental settings, however, and frequently involves people who have not benefited from recent ways of working (Rondal & Comblain, 1996; Buckley 1993). No two individuals are ever the same, either, and their capabilities can change depending upon context. Despite these reservations, it is possible to construct a reflective framework for practitioners (see Table 1) to help them ask questions of their own practice in relation to auditory, language and memory characteristics identified from the research base (Rix, 2005, 2004).

Table 1: Possible enabling and disabling factors using auditory and linguistic characteristics identified through research with people with the Down syndrome label (based on Rix 2004, 2005)

Possible enabling factors?	Possible disabling barriers?	Characteristics from Research Base
- Use of visual input when teaching - Encouragement of subvocal rehearsal through repetition in text - Use of repetition to establish names, terms, & concepts - Use of short words & sentences - Limit the number of concepts, names etc discussed per section - Attempt to have a maximum of two referential concepts, names etc per text section - Anticipate possible confusion through pronoun use & consider using the proper noun to refer to the key person or item - Define clear, obvious points of reference & limit the need for switching focus - Use short sentences – one clause better than two - Use simple sentences - Use familiar words - but define familiar with care - Use words of one or two syllables - Try to use single consonant words - Define possible new words - Reinforce new words through repetition so they become familiar - Reinforce the most significant words - Use alternative words to explain meaning through context - Use alternative words to reinforce meaning through context - Consider possible alternatives meanings for words -eg Cannon/Canon - Avoid the passive & negative forms - Use of sign supported language	- Reliance upon auditory input - Poor diction and clarity of speech - Presenting information when there are distractions - Use of complex sentences with a number of different concepts or individuals referred to - Use of long sentences - Use of broad vocabulary - Use of long words - Complex use of pronouns & proper nouns - Using negative & passive sentences - Introducing new words - Introducing dual tasks - Introducing a wide number of new skills - Lack of possibilities to practice skills - Relying on new skills - Relying on memory alone - Unfamiliar situations - Assumptions about knowledge and vocabulary - Requiring a rapid response - Lack of signing	- Expressive language skills of a typical 3 - 5 year old - Effective pragmatics - Reasonable lexicon - Suggestion of reasonable comprehension - Poor morpho-syntax - Limited word recall - Simple sentences used - Reduced production of pronouns & auxiliary verbs & subordinate clauses & conjunctions & negative & passive sentences - Complexity of extra-linguistic content and context correlates with language difficulties - Reduced definition of short stop consonant words - Two syllable non-word with consonant clusters poorly recalled - Repetition effected by word length and familiarity of word - Word differentiation reduced by close following noise - Difficulty learning new words - Difficulty in differentiating brief and quiet sounds and short words - Tendency for avoidance strategies in complex situations - Hesitancy to use new skills - Gestures support understanding - Gestures support expression 40% mild hearing loss 15% severe hearing loss 12% will have restrictions above 4000hz - Higher decibel level required - Distortion of sound - Muffling Effect - Fluctuating Condition - Reduction in sharpness - Slower response to auditory stimuli - Slower move initiation with auditory stimuli - Usually a faster response to visual stimuli - Average MLU of 3 – 5 - Short term memory of 3 - 4 digits - Not an attention or concentration problem - Reduced sequential processing - Reduced rehearsal mechanisms - Poor subvocal rehearsal - Potential operating speed reduction - Potential reduced store - Potential unusually fast decay of information - Ambiguous use of referential forms with more than 2 characters involved - Thematic Subject Restraint is often reversed - Language skills below cognitive test score levels

And still they are one of many…
The problem with this table is that it is partial. Where is the information for art, or sport, or foreign languages or numeracy or going on school trips and so forth? Within an educational setting, practitioners need to take a broad view of the individual child. Consider for example the research that confirms that gestures are more efficient vehicles for expressing understanding than verbal expression alone, and that people diagnosed as having Down syndrome will frequently supply the correct gesture alongside unintelligible productions (Stefanini, Caselli & Volterra, 2007). Such a finding underlines the importance of sign supported language. But surely a teacher also needs to bear in mind the research which highlights high rates of visual impairment, and a tendency to tire more quickly when looking at items (Pueschel & Gieswein, 1993)? Ironically, too, this separation as a pedagogy for this identified group has the potential to mask the relevance of these approaches for a wide range of students. For instance, Wang, Bernas & Eberhard (2001, 2004) have shown how use of symbolic hand gestures has a positive impact on engagement and academic outcome for both children with the ADHD label and the Down syndrome label.

In creating 'expert' guidance we are always in danger of implying that there is one way to know a particular group of people and that their needs are in some way different. For example, much is made of whole word strategies to teach reading to children defined by a Down syndrome label, but this can be of value to their peers too, and ought not hide the increasing evidence that everyday phonics is a key tool as well (Joseph & Seery, 2004; Van Bysterveldt, Gillon & Moran, 2006). When we provide teachers with activities designed specifically to develop any particular aspect of language, these ought to be delivered within an overall pedagogical framework which reflects the underlying continua of teaching approaches evident across 'specialist' programmes (Lewis & Norwich, 2000, 2001). They would therefore be aiming to provide for a wide range of students:
1.   more practice to achieve mastery
2.   more examples to learn concepts
3.   more experience of transfer
4.   more explicit teaching of learning strategies and reinforcement of them
5.   more frequent and more specific assessment of learning
6.   more time to solve problems, and so on
7.   more careful checking for preparedness for next stage of learning.

(Lewis & Norwich, 2000, p32)

In so doing, the use of signing and gesture, for example, and all of those other possible enabling strategies are enabling not just one child in isolation, but a range of unidentified students in the setting too.

Being creative and reflective
Placing a child within a mainstream setting is not a magic bullet. To be effective it requires reflective practice on behalf of all staff involved. Rietveld (2005), for example, identified teachers frequently praising children catagorised as having Down syndrome when they had got something wrong, as well as for being busy and on-task. Often the children had no idea what they were being praised for. This might be considered an inappropriate application of the recommended errorless learning techniques (Duffy & Wishart, 1994), but to Rietveld it was evidence that there was little monitoring of the children's learning. Practitioners need to be aware of the assumptions which they carry with them, and the manner in which their actions pass these assumptions on to those they work with; colleagues, students and parents.

In delivering effective mainstream education, there needs to be a collaborative network, extending both within and beyond the setting, which has a shared understanding of the aims and processes being undertaken (Nind & Wearmouth, 2004; Sheehy & Rix, 2009). My son has the Down syndrome label (and the 'red head' label…and the 'very loud' label…and the 'swimmer' label…and quite a

few others too). At time of writing, Robbie is 8 years old and in mainstream primary school. He does not talk intelligibly and rarely chooses to initiate meaningful discussions. The speech and language therapist (SALT) who visits the school feels that Robbie needs to be encouraged to talk with his peers and with staff. But how? In a meeting with the SALT, class staff and parents (but not Robbie or his peers?) we discussed how this could be achieved. As parents, (as an academic, should I be considered a critical friend?) we suggested combining work on reading with work on speaking. The staff could create a number of key sentences which had meaning in the context of the day, which Robbie could read out at appropriate moments. We identified those key sentences, and the next day the staff produced them and started using the materials. Robbie immediately engaged with them. A very successful strategy. But not one that came from research or specific understanding of a syndrome. It required a creative moment. This came from a group of people who had some time together, who had a collective understanding of the child, his learning situation and his personal characteristics, had insights into pedagogy and language, who shared a goal, and approached a barrier as an opportunity for learning. Importantly too, the outcome was one which focused on the inclusion of the child, bringing him back into the class, and the teacher's main frame of reference.

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Continuing Education Questions
Question 1:
Which of the following is the most likely to result in effective interaction with children with special educational needs?
1. Extensive training
2. A broad knowledge of syndrome types
3. Experience with different groups of people
4. Having a positive attitude towards the inclusion of children with SEN

Number 4 is correct

Question 2:
Which approach will facilitate the inclusion of a child identified with Down syndrome within a mainstream classroom?
1. An expert teaching assistant taking responsibility for their learning
2. An expert external advisor providing clear guidance on different learning profiles
3. A class teacher taking responsibility for planning and teaching
4. A personal work area for the child

Number 3 is correct

Question 3:
Involvement in collaborative learning activities will be effective if:
1. Students are carefully matched according to ability
2. Teachers delineate group roles and plan for social interaction
3. Teaching Assistants always support the children with SEN
4. Only academic outcomes are focussed upon.

Number 2 is correct

Question 4:
What is the difference in expressive language between students educated within the mainstream and those with segregated provision?
1. Mainstream students will be 2 years and 6 months behind.
2. Mainstream students will be 2 years and 6 months ahead.
3. Mainstream students will be 6 months behind.
4. Mainstream students will be 6 months ahead.

Number 2 is correct

Question 5:
Which of the following is an honest response to teachers who believe that they do not have the skills they need to teach students with SEN.
1. These skills only come with considerable training in different specialist areas
2. These skills only come from external experts
3. These skills need to be provided to another member of staff to support you
4. These skills come from the continua of approaches you use already

Number 4 is correct