

Keeping Declan reading

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"A friend of mine, who has a 19 year old son with Down's syndrome, asked me if I knew of any suitable reading books for this age group. When her son left school, he announced that he wasn't going to read any more books - I suppose this reaction could come from any young person! However, my friend is wondering if the reaction is more to do with the fact that books written for ordinary teenagers/young adults are beyond her son's capabilities whilst the books he can manage are too childish in content and, therefore, demeaning for him. She is also concerned that reading is a skill which needs to be practised, she doesn't want her son to lose that skill. Does anyone know of any suitable reading material for teenagers/young adults that would fit the bill?"

When this question appeared on the UK Down Syndrome email list early in 2003, I was compelled to reveal all about my son's reading and TV/movie habits, and I have added some further thoughts about the importance of reading to this 17 year old who is not fond of 'school work'. It's not a prescription for teenage reading, just our experience, grown out of Declan's natural inclinations and

access to good quality information made readily available to families like ours.

Declan (17) is a huge James Bond fan. His favourite book, which he knows extremely well, but enjoys re-reading often, is *"The Secret Life of Agent 007"*, published by Dorling Kindersley. A large, 'coffee-table' format, it is filled with photos and drawings of every James Bond movie (except the most recent one), locations, Bond girls, villains, internal drawings of the various devices that Bond uses to save the world and that the villains use to threaten it. Not too many words, and the pictures are great. Often he reads with and to his Dad, a closet James Bond fan. He never asks me!

Declan remembers all these details, reinforced by his assiduous watching of the movies (he has the whole collection on video!), reading of *"The Book"*, playing of the Nintendo 64 games, and his growing collection of fortnightly Bond magazines. Yes he does a lot of other

stuff too, but this is a favourite form of relaxation!

You can take a look at The Book here (some editions do not have the red cover): <http://uk.dk.com/Book/BookFrame/0,1007,00.html?id=075132860X> (or just put James Bond into the search box at <http://uk.dk.com>)

A number of Declan's friends who also have Down syndrome have envied this book so much (as he did when his friend had it before him), that we have given it as a birthday present to a number of them from about 15-17 years old. It is getting difficult to find here in Sydney, so when I came across 6 copies in the New Year sales, I bought them all, to pass on to others. And not all of the recipients have disabilities – there are lot of very strange people out there who are also huge James Bond fans!

A children's book that he still gets a lot of fun out of is *"Bamboozled"* by David Legge (Ashton Scholastic, 1994, now out of print according to amazon.com, but you might be able to find it in a library). It is a simple story, with wonderfully clear, colourful drawings of very silly scenes, with many, many things to laugh at in each one because they are so obviously ridiculous – a garden bed full of bulbs (light bulbs!), chairs with bumper bars, a mat that is actually a fish pond – it's hard to describe how entertaining it is! In addition to the sheer fun and giggling, there is so much to talk about – what would happen if you stepped on that mat? Would you wash the dishes under an elephant's trunk? Look at him mowing the carpet ... so many funny things. The reading of the words is the least part of the enjoyment, but still good fun, because the girl and her grandfather, whose house is the setting, cannot work out what is 'odd today', and don't think any of the scenes are strange at all.

It is worth checking with specialist bookshops (or teaching supplies stockists) for 'high interest - low ability' readers. I've looked at a number

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of series, although some of them are still too difficult to motivate Declan to really sit and read them, and some of them are just too difficult.

We also like the CD-ROM reading package "Spin Out Stories" of interactive high-interest/low ability 'books' and other reading activities, aimed at junior high to high school ages. Declan particularly likes the stories about trucks and road building. Declan's school has bought both packages for their senior library, and the older kids really do like them. The publisher, Greygum, is in Australia, but has a distributor in the UK. Further details: www.greygum.com.au

I have written a review that is available at: http://members.iinet.net.au/~dsansw/spin_rev.html

Declan is at best a reluctant reader and writer, and a long way from the most accomplished of other young people with Down syndrome of his age. However, his speech is better than many, and his social skills are outstanding. These, along with good motor skills and good health, are his innate gifts, that have been relatively easy to nurture.

When Declan was 8 weeks old, we enrolled in an excellent community-based early intervention program based on the Macquarie University program, and he progressed to mainstream preschool (with support) and very early school experience, followed by most of primary school enrolled in a supported class in a mainstream school, and high school at a special school.

He learned a number of sight words at early intervention, but we did not embark on an intensive early reading program, although he was exposed to many books and a lot of reading from an early age, and saw us reading constantly.

There has always been an academic component in his school program (sometimes we have had to insist on its inclusion in his IEP), and a language rich environment at home – but he still finds reading and most other academic work difficult and he says, "boring". I think boring means a combination of difficult and not always well-matched to his interests. To keep Declan reading just for the sake of keeping up the skills, or as a performance would simply not work – it has to have a purpose that he can appreciate and that he values or he just won't do it. The last thing

we want to do is to make reading a punishment or even a chore. I think he'd agree with the young man about whom the question of suitable reading materials was posed.

His current school suits him very well on the whole, but he does complain when he has to do 'school work' all day – he wants to do 'real work' (a job), which he values much more. He is happier with work experience, TAFE (Technical and Further Education) college and excursions into the community, all of which now occur as part of the school program. He will be leaving school one week after his 18th birthday in December 2003, much to his delight. He insists that we refer to school as his 'work', and says he's off to 'the office' each morning. He doesn't hate school by any means – he's just really upfront (and I think quite articulate) about the need for it to have practical meaning for him. This year, he is the school captain, and having a great experience being an acknowledged leader – "I'm responsible", he tells us proudly and appropriately.

To keep him reading and writing, we have developed (under Declan's guidance, and in response to his level of comfort) a range of activities that make sense to him. Motivation and personal interest are *everything*:

- he can read a TV program from almost any source. The layout doesn't seem to present a problem, and he can locate any football game, in any code, on any channel, any day of the week. He can tell you the time, and the teams playing, and always has an opinion about who will win and whether we should watch it. The rest of us rarely need to consult a TV guide – we just ask Declan.
- he goes to the newsagent alone, buys the broadsheet newspaper that we like, and can make sure that he gets all the components of the jumbo Saturday edition (most of which we throw away!). 'Declan's' part of the paper is the sport section (where he checks the National Rugby League table, and occasional cricket scores, to make sure we've thrashed the Poms), and the movie guide. He has no trouble locating, in a major metropolitan paper, our local cinema complex by the name of the chain and the name of the suburb, and finds both the movie he wants

to see and the most appropriate session time, despite the small print, marked short sightedness and often less than clean glasses. Meanwhile, his father and I have to peer at the increasingly small print under a 100 watt lamp with a magnifying glass.... He buys himself a rugby league magazine during the winter (he doesn't read much from the articles, but really does concentrate on the photos, team listings and points tables – a bit different from the stereotyped male magazine buyer who is supposed to say that he buys them for the articles!), an occasional soap-opera magazine or TV Week, and has ordered the fortnightly 007 magazine series, which is currently up to issue number 17(!) Emma, Declan's sister, buys a monthly teen magazine that is much more targeted at girls than boys, and they share it – the back issues are kept in Declan's room because Emma objects to him going into her room to 'borrow' them when she's not home.

- both Declan and Emma, who is 12, like to have the week's menus provided in advance (they'd both be happy to live a high class hotel, I'm sure), and often produce one either alone or in collaboration. Emma is often required to be the writer, but takes instruction well. You can be sure "let's eat in a restaurant", or even just the name of a local favourite eating place will appear at least once. They post it on the fridge door, and insist that we stick to it – it is The Word.

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Declan and Emma collaborating on a weekly menu



- restaurant menus are more of a challenge, but Declan likes to have his own copy and to make his own choices from what he can read. He usually prefers to talk with the waiter himself. Of course the dreaded Golden Arches menu appears have been indelibly imprinted on his brain soon after birth.
- from a young age, Declan was provided with a healthy collection of music on cassette, vinyl and later CD, and an enviable video library by indulgent grandparents. From a very young age he

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could produce exactly the one he wanted, even if it wasn't in its cover, and looked exactly like all the others to us.

To confuse the issue further, he had made up titles for them all

(different from the real ones), that he expected us to know and understand, even when his speech was barely intelligible. Now that he speaks clearly he sticks to the real titles, and we have some mild disputes about the suitability of the video ratings from time to time. He likes to have M or MA rated movies, largely because they are recommended for over 15 year olds, and 'the child' (Emma) should not be allowed to watch them since she is not mature yet (unlike him). So being able to read the classifications helps him to assert his place in the pecking

Declan keeps a birthday list throughout the year, starting right after one birthday, ready for the next

order. He catches us unaware sometimes, with the words he recognizes. When the first Harry Potter movie came out on video, we saw it on a store display for the first time,

and Declan immediately asked (with some disdain) on reading the cover, "What supernatural themes are in Harry Potter?" suggesting that he'd either missed the point or didn't really understand what "supernatural" meant although he could read it.

- we have collected a number of card decks, with increasingly age-appropriate illustrations, and sometimes words, and Declan enjoys memory games such as "Concentration" and simple card games. Currently we have cards

based on TV characters, an Old Maid set of adult occupational caricatures, and card sets with photos of animals, vehicles and dinosaurs published by Dorling Kindersley. Some of them I have found in a shop selling games and puzzles intended for gifted children, some were in chain stores. We also have some old favourite board games that I think help maintain reading, memory and thinking skills: Guess Who?; Upwords (a version of Scrabble); Trouble; and Junior Monopoly (we use an Australian set). Declan often elects to be the score keeper, gaining some painless writing practice.

- he uses both public and private telephones competently, as long as he has the number in a written form. He can work from the Filofax at home, a short list or a business card, and, like many other youngsters with Down syndrome, his speech is even clearer on the phone than at other times.
- he travels independently to school and home again, on a public bus. On the trip home he often gets on the bus at a busy interchange, and he has to recognize the number and destination, and check the timetable, as he gets it at a time that the routes take a minor change at the start of the peak hour. (One day he caught a very early afternoon bus and was very grumpy that it had gone down the 'wrong' road, even though he still got off at his regular stop. I think the driver was probably less than pleased that Declan pointed out to him that he had 'stuffed up' the route!)
- two examples motivated entirely by self-interest: Declan keeps a birthday list throughout the year, starting right after one birthday, ready for the next. The entries are a mix of his handwriting and various other family members' who he cons to help out from time to time. He nurses it carefully, and brings it to our attention often, just in case we forget. Writing the list gives it great legitimacy in his eyes, although he does understand that he will not get everything on it. The second is probably not reading, but Declan can tell the difference between a five and a ten dollar

note at a glance (one is purple, and one is blue), and "I'll take the tenner thanks".

Please don't tell him that any of these activities are 'good for him', or have anything to do with school-work, and I hope he never finds out that he could have legally finished school at 15!

In an earlier question on an email list, a parent had worried that her child's speech and language development might 'stall' at some stage (around seven). That might have been suggested to her – we still hear such outdated and simply ill-informed pronouncements from the most surprising sources. We also sometimes hear it said (usually by teachers) that children with Down syndrome who aren't reading by 12 – or whatever age the child conveniently is – will never learn to read, so "we don't do literacy". And then they don't learn – a self-fulfilling prophecy if ever there was one.

I hope that my note about Declan's obviously continuing development of communication skills and the range of literacy and language activities that he encounters and enjoys on a daily basis helped to encourage her and to allay her fears.

We haven't done intensive formal speech therapy (he hasn't seen a speech and language therapist since he was not quite five – I don't count the very infrequent and token visits by the school therapy teams of our experience), but he has had a lot of communication opportunities and a great deal of language input, both at home and school, and he's lucky to have none of the more complex difficulties of speech that some people with Down syndrome have to deal with. His hearing is good, and we have been aware of its importance from a young age, because of our knowledge of Sue Buckley's work on language development, (and research on the utility of reading to promote language development).

When Declan first went off to school at just over five, barely using two word phrases consistently, we hardly dared hope that he would ever be able to speak as well as he can now, let alone read for pleasure (well a bit, anyway!). In a family that tends to be 'bookish', it's nice to see that sometimes it's Declan with his 'head stuck in a book' ignoring the world, even if it is James Bond.

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Of course I don't know exactly what impact being an active, if sometimes reluctant, reader has had on Declan's continuing language development, but I'm sure that it has helped, and I am pleased for all of us that his vocabulary, syntax, grammar and abstract thought processes are still developing at a noticeable rate, at the grand old age of 17½.

The combination of communication and reading skills matters to him because he knows he's developing competence and more adult skills, and it makes his way in the world easier. Literacy and language might be the difference between a job he really wants and one that's all that's offering. If he doesn't need to read and /or write for the job he wants to do, keeping up his reading skills will certainly make other aspects of his life easier - even the ability to make a phone call independently with a printed number can give him a measure of adult privacy and control that many people with intellectual disabilities never enjoy.

So how will we keep him reading?

- by not reading for him when he can do it,
 - by providing as many opportunities as we can,
 - by continuing to read with him,
 - and by paying attention to his motivation and interests
- Why else would he bother?



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Reading resources

The following items are available from The Down Syndrome Educational Trust:

Reading and writing for individuals with Down syndrome – An overview. By Sue Buckley (2001). Portsmouth, UK: The Down Syndrome Educational Trust. ISBN: 1-903806-09-7.

Reading and writing development for infants with Down syndrome (0-5 years). By Gillian Bird and Sue Buckley (2001). Portsmouth, UK: The Down Syndrome Educational Trust. ISBN: 1-903806-10-0.

Reading and writing development for children with Down syndrome (5-11 years). By Gillian Bird, Jane Beadman and Sue Buckley (2001). Portsmouth, UK: The Down Syndrome Educational Trust. ISBN: 1-903806-11-9.

Reading and writing development for teenagers with Down syndrome (11-16 years). By Gillian Bird and Sue Buckley (2002). Portsmouth, UK: The Down Syndrome Educational Trust. ISBN: 1-903806-12-7.

Oelwein, P. (1996). *Teaching reading to children with Down syndrome - A guide for parents and teachers.* Bethesda, MA: Woodbine House.

References to Latch-On Australian project

Van Kraayenoord, C.E., Moni, K.B., Jobling, A. & Ziebarth, K. (2001). Broadening approaches to literacy education for young adults with Down syndrome. In M.Cuskelly, A. Jobling, & S.Buckley (Eds.) *Down Syndrome Across the Life Span.* London, U.K: Whurr.

Gallaher, K.M., van Kraayenoord, C.E., Jobling, A. & Moni, K. (2002). Reading with Abby: a case study of individual tutoring with a young adult with Down syndrome. *Down Syndrome Research and Practice.* 8. 59-66.

Useful online resources

The National Literacy Trust

<http://www.literacytrust.org>



The Reading Village

<http://teams.lacoe.edu/village>



The Adolescent Literacy Learning Link

<http://www.med.unc.edu/ahs/clds/projects.html>



see also the main site for **The Centre for Literacy and Disability Studies, University of California**

<http://www.med.unc.edu/ahs/clds/>

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