# Letters to the Home Front

Positive Thoughts and Ideas for Parents Bringing Up Children with Developmental Disabilities, Particularly those with an Autism Spectrum Disorder

## Contents

ACKNOWLEDGEMENTS	9
Introduction Overview of the book	11 12
Section 1 Letters to my family Three young people on the autistic spectrum reflect on	
their growing up	17
A. Dean's letter B. Hannah's thoughts	18 21
C. Alex's letter Section comments	23 28
Section 2 Dear all  Considering some general topics and decisions that come up in the parenting process	29
A. The road ahead  Looking at how the parenting agenda  changes over time  B. Who are you?	29
Reflecting on how to see real people in the midst of significant and widespread differences in abilities and the diagnostic labels that often accompany these differences C. Brothers and sisters	38
Considering the impact on siblings of growing up with a brother or sister who significant developmental disabilities	46

D. Managing the system	
Thoughts about dealing with the challenges that arise for	
parents having to deal with multiple professional agencies	
over long periods of time	52
E. Got behaviour – get drugs?	
A guide to help parents think through the issues that arise	
when they are offered medication to help control their son's	
or daughter's behaviour	60
Section 3 Letters to parents	
Thinking about behavioural challenges presented by children	
and young people on the autistic spectrum	67
A. Charlene ('obsessions')	68
B. Marcus (physical aggression)	73
C. Tyrone (verbal abuse, physical aggression,	
property damage)	79
D. Charlie (a danger to self and others)	87
E. Rudy (long-term severe self-injury and physical	
aggression)	92
Section comments	99
Section 4 Epistles on challenging	
orthodox thinking	101
A. Sensory integration – brain changer or licence to	
twiddle?	102
B. Boarding schools in the $UK - a$ solution for	
difficult problems or a British disease?	109
A few last thoughts	117
Appendix: Constructive behavioural support:	
Service evaluation guide	121
RATING AREAS	122

### Section 1

# Letters to my family

Three young people on the autistic spectrum reflect on their growing up

I asked three articulate young people on the autistic spectrum to reflect on their growing up and to write a letter to their parent(s) about the things that they appreciated and found helpful and the things that were problematic or that could have been done differently. Dean, Hannah and Alex responded magnificently. Hannah found the letter format did not really work for her so she has crafted something that enables her to express herself in a way that is more valid for her. What is extraordinary here is the level of awareness that these young people show about the support that they received, an awareness that would not have been obvious at all to their families at the time. At the end of each letter there are brief biographical details about each of the young people as provided by the authors themselves.

# A. Dean's letter Mum,

As you know, I speak at conferences all over the UK about my experiences of Asperger's syndrome, and the one comment I get again and again is 'Your mum must be so proud of you...' I know that you are – against the odds.

We didn't have the easiest of starts, did we? As a baby, my sleeping pattern left a lot to be desired, and it never really improved. It must have been an absolute nightmare trying to get a hyperactive six-year-old off to sleep when all he wanted to do was watch *Doctor Who* until the early hours! Eventually, you gave up work altogether and I can't help feeling like that was my fault – you sacrificed your career in order to be at home with your extremely challenging child. And challenging is definitely the word! Refusing to get in the bath, standing at the top of the stairs screeching like Kate Bush, aggressive, defiant... I don't know how you did it!

And once I was at school, things only seemed to get harder. Despite you devoting all of your time to bringing your children up, you faced accusations from professionals that my bad behaviour was down to your parenting. That must have hurt. Bringing up a child with special needs can be the most challenging job in the world, and to have been endlessly demoralised by authority figures whilst you tried to do that would be enough to crush anyone. But not you.

You may not have been an expert in Asperger's, but you were an expert in your child, and you fought tooth and nail to get me the support I needed. You knew that with the right support I could thrive in mainstream and you battled for me to remain there, despite the authorities pushing to put me in a special school. You knew special school wouldn't be right for me and you stuck to your guns. That takes guts. You were endlessly told that I'd achieve nothing and that I'd end up in prison, yet your belief in me never faltered. Even when my 'Carry On' film

obsession resulted in me pinching every bottom in sight, you refused to accept the 'sexually inappropriate' label that was attached to me. You knew I was just copying what I had seen on TV and trying to get a reaction. You were firm with me, and disciplined me, but you also tried to understand my behaviour too, because the best way of solving a behavioural issue is to find out the cause. You saw the person beneath the challenging behaviour and you encouraged him, supported him and more than anything you loved him.

And although I've always loved you deeply, I guess I haven't always been great at showing it. In my younger years I was prone to violent outbursts and it still shames me to admit that I punched you in the face twice. I'll always regret that. And do you know what? You were never bitter about it. You never bore a grudge. There must have been times when I seemed so ungrateful, uncooperative and unpleasant and yet you kept going. I guess that's the biggest lesson I've learned from you in life, Mum, to never give up. To see the goal and keep going for it until you achieve it.

I know that you struggled to tell me about my diagnosis. You weren't sure when would be the right time to tell me about having Asperger's, and I can understand that totally. As a child who never wanted to be perceived as different, you knew it would be earth shattering for me to find out that I had a disability. In hindsight I wish you'd told me straight away, but I fully understand why you didn't. What matters most to me is that you never portrayed Asperger's in a negative way. You were always totally positive about my diagnosis and never allowed me to see it as a set back. And that's no mean feat when I'm sure you were worried about my future at times yourself.

Despite six suspensions from school, changing schools and depressive bouts in my early teens, somehow we got there, didn't we? With the support of a great team at my secondary school and a fantastic music therapist, we turned it all around and I got ten

A\*-Cs at GCSEs and three A-Cs at A Level. I say 'we', because although I did the work in the classroom, it was only due to you fighting for me that I was allowed into one in the first place!

I now have a good circle of friends, a great relationship and a career. I've toured the country as a speaker and have been published in four countries as a journalist. Not bad for 22, eh? And not bad for a child who was proclaimed a monster. It feels like an even bigger achievement because, in my heart of hearts, I know that if it hadn't been for your love and determination, things would have been very different.

You indulged my many obsessions (even though I'm sure they bored you to tears at times! Who wants to hear about *EastEnders* ad nauseam for 12 months?), you encouraged my sense of humour and most of all you were one of the only people who focused on what I could do rather than what I couldn't. Most importantly you never referred to me as your 'autistic child'. When my diagnosis came, you didn't treat me any differently, because you saw me as a person. Your son, Dean.

I get comments all the time from my peers about my relationship with you. They can't believe how open I am with you. But to me that's a great compliment, because I feel that our mother—son bond has matured into a strong friendship as I've grown into adulthood. Who'd have thought it?

So when I'm asked, at those conferences, whether you're proud of me, I always say the same thing: 'I hope that she is, because I'm totally proud of her.' I love you, Mum

Dean xxx

### About Dean

Dean Beadle tours the UK giving keynote, motivational and after-dinner speeches at conferences, meetings and training events. Having spoken everywhere from Lincoln and Liverpool to Essex and Edinburgh, and most places in between, he speaks about his experiences with Asperger's syndrome; discussing how he developed from a child considered a 'monster' to an A-Grade student. Dean encourages his audiences to see the condition in a much more positive light, through his humorous and poignant anecdotes. In 2011 Dean's speaking brought him to a global audience, as a clip of one of his speeches has been viewed in 75 countries worldwide on YouTube.

Aside from speaking work, Dean is an experienced journalist. He has written articles based on autism for *Cerebra Bulletin* and *NAS Communication Magazine*. He also resided as an online columnist for special needs website www.snapchildcare.co.uk for 18 months. Between 2008 and 2010, Dean was a columnist for commercially released magazine *Autism File*, which was sold in retail chains across the UK, Australia, Dubai and North America. He has also written general news articles and features for www. newsshopper.co.uk and *the londonpaper*. Throughout 2009 he had an economising column in *Greenwich Time* newspaper called 'MR BUDG£T' and between January and May 2010 he had a diet and fitness column in the same publication entitled 'Lighten Up!' Dean has also written book/music/live reviews for the publication.

Most recently he has branched out into presenting work, having presented an online resource for TwoFour Media/ The Teaching Development Agency.