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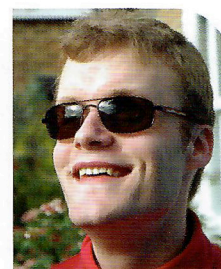
Dad's view: wish you were here!

Educational psychology **new series**



In the Key of Genius (Part 1)

In May this year, Adam Ockelford's new book "In the Key of Genius: The Extraordinary Life of Derek Paravicini" was published in print by Hutchinson, and in braille and as a Daisy book from RNIB.



Derek today

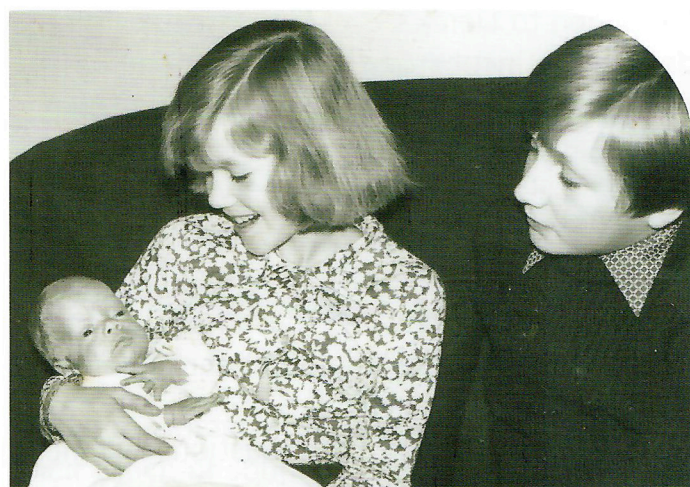
In the first of three short excerpts from his book, Adam charts episodes from Derek's early life.

Today, Derek is a young man with exceptional musical abilities, despite being blind and having severe learning difficulties. His piano playing regularly thrills audiences in the UK, Europe, the United States and beyond. He is widely fêted in the media as a "prodigious musical savant" – and he lives a rich, varied and fulfilled life, relishing the stream of new experiences that his music-making offers.

But things were not always so good. Derek had a very difficult start as the most premature baby to survive in his home county of Berkshire, and "died" several times in the incubator before finally pulling through. His family didn't know what to make of his eccentric behaviour as a toddler, and puzzled as to the best way of supporting his development.

Baby Derek always slept well, for which Nanny was thankful, though he still seemed wholly unconcerned about the dark, which continued to puzzle her. One night, when he was obviously still awake, she deliberately switched the light back on and then off again. As ever, there was no response. Once more, on and off. Nothing.

"Mary Ann!" Despite her ever-present composure, Nanny couldn't disguise the anxiety in her voice. "Mary Ann! I think there's something wrong with Derek's eyes." "Nonsense!" Mary Ann came upstairs, though,



Derek as a baby, 1979

and turned the light back on so she could scrutinise her young son for herself. There he

was, lying with his eyes open, contentedly looking at the ceiling, or so it seemed to her. She waved her hand in front of his face. He didn't respond. She tried again, her hand closer this time. Still no reaction.

"Derek!" she said, apprehensively, and at last he did respond, startling to the sudden sound of her voice. Both women looked at each other, though neither said anything. Eventually, Nanny turned and switched off the light. "Come on," she said, "We'll phone the doctor in the morning."

It was two long weeks before the family's worst suspicions were confirmed. Nic and Mary Ann had to take Derek to London's Moorfields Eye Hospital to be seen by a paediatric ophthalmologist. He would have to be examined under anaesthetic, a distressing prospect. But the examination didn't take long, and afterwards the consultant came

straight to the point.

"I'm sorry to tell you that your child is blind."

A stunned silence followed. Nic glanced at Mary Ann, his mind reeling. He had been hoping that Nanny and Mary Ann had somehow been mistaken.

"Can anything be done?"

"I'm afraid not." And the doctor proceeded to give a technical explanation of what had happened to Derek's eyes during those long days in the incubator. He had developed a condition called retrolental fibroplasia (today known as retinopathy of prematurity or "RoP"). This had resulted from the uncontrolled levels of oxygen in his blood, which had caused certain vessels in Derek's eyes to grow abnormally. These had damaged Derek's retinas – the thin, light-sensitive films at the backs of his eyes.

Nic wanted to ask another question, but the consultant was in full flow.

Normally, the retina was made up of over 100 million receptors called "rods" and "cones", which sent messages down the optic nerves to the brain. In Derek's case, however, the retinas had become detached as a result of the scarring ...

Nic interrupted him. He had to know.

"So there really is no hope at all?"

The consultant met Nic's gaze with some difficulty.

"No. I'm sorry." He paused briefly and then added: "I'll register him today."

The drive home through the London rush-hour seemed interminable, the gloomy silence in the car broken only by the bustle of the traffic outside. Nanny listened intently to Mary Ann's fractured account of what had been said. Stoical as ever, she had already been planning what to do.

Toys that make sounds, that's what he needs, she thought, and as Nic pulled out on to Hammersmith Broadway, she started to make a mental note of the possibilities.

That night, Nanny made another decision:

since Derek couldn't see her, whenever she wasn't physically in contact with him she had better keep in touch by talking or singing. And so she got into the habit of telling him everything that she was doing, what was in the room around him, what she could see out of the window, what the weather was like, and so on. And when Nanny wasn't talking, she was singing: all the nursery rhymes from her vast repertoire, songs from the shows insofar as she could remember them, and popular songs from her youth. At first, of course, Derek didn't know what any of this meant, but he quickly got used to Nanny's voice – a constant mellow stream in a complex and ever-changing auditory landscape – and by the time he was three he could do a creditable impression of her "warbling"!

Intuitively, Nanny intensified the daily routine, helping Derek to anticipate what was coming next by letting him smell his clean clothes before dressing him, for example, and always remembering to tap her fingers on the bottle before feeding time. Over the weeks and months that followed, Derek grew accustomed to these and a range of other household sounds too: the radio in the utility room that Alice, the daily, liked to have on while she did the ironing; the television in the drawing room; and, in time, Derek's own "noisy toys". Nanny had purchased just about every conceivable sound-making toy for him, though Derek didn't seem to play with these at all in the conventional sense, she noticed. He wasn't interested in exploring what she gave him in any systematic way or testing it to see what it could do. Derek would simply bang whatever was handed to him on anything that was available: the tray on his high-chair, the floor or another toy. He would keep going relentlessly until even Nanny's patience was exhausted.

Derek's fingers, though still tiny, were extraordinary too. They were constantly on the move, curling and uncurling and twisting over



Derek with his sister on holiday

themselves like the tentacles of a baby octopus. His hands also developed some habits that made less comfortable viewing. Sometimes, clenching his fists, he would push them hard into his closed eyes. On other occasions, he would put both thumbs in his mouth and extend his forefingers upwards, poking at his eyelids. Strangely, these behaviours seemed to cause Derek no distress, and if anyone gently tried to lower his hands from his face, then they invariably found their way straight back up again. At the same time, when he was lying down, Derek's head would weave relentlessly from side to side. And later, once he could sit up, he would rock to and fro as well. Why does he do this, Nanny wondered. In all her years of bringing up children she had never seen behaviour like it. Perhaps it was usual for blind babies? After all, he couldn't see what he was doing (or what anyone else did, for that matter). Or perhaps there was more to it than that – but this was a line of thought that she couldn't bear to contemplate, so instead she picked up her "Blessing" (as she referred to Derek) and gave him an enormous hug. He giggled with pleasure. For above all, despite his penchant for self-stimulation, he loved human company:



Derek age one, with his mother

to be in contact with other people through their touch or sound or scent (later, as a child, he would identify people first by smelling their hands). He relished being held and tickled and bounced up and down. And he delighted in hearing familiar voices, which for him signalled the presence of family or friends, many of whom were to remain loyal companions throughout his childhood and beyond.

At first, having heard that Derek was blind, those who had previously dropped in to see him without giving it a second thought now approached the nursery with some awkwardness – trepidation even – but no-one could feel sad or sorry for Derek for long: from his earliest days at North Lodge Farm, he seemed to exude a natural charm that people found captivating.

It hardly seemed any time at all before Derek's first year had passed and his birthday was due – albeit three and half months before it should have been. It seemed incredible now that he should have been a November baby. The 26th July dawned grey but fine, and Nanny was up particularly early to make sure that all was prepared and perfect for the afternoon's party.

Amid the balloons and the jelly and the birthday cake, Derek gurgled happily, absorbing the sounds of excitement around him and banging the tray on his high chair with his spoon. Nanny was attentive as ever, ensuring everyone ate their fill and leading the singing of "Happy Birthday". Libbet helped Derek to blow out the solitary candle. Charles, his brother, assisted in cutting the cake. Nic and Mary Ann chatted convivially with their guests.

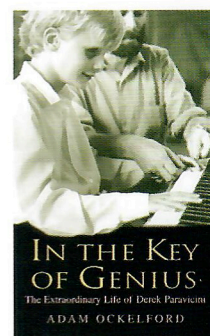
But deep down, although they hadn't yet confided in each other, the three adults were increasingly wondering what the future might hold for Derek. He seemed to be rocking more and more these days and his fingers rarely left his eyes. There were strange depths to the young boy that they couldn't fathom. Whenever he was left alone he appeared to retreat into an inner world whose nature they could only guess. At these times, Nanny yearned to see behind those sightless eyes and into Derek's mind to find out what he was

thinking! Unbeknown to her, the clues were already there, but it would be some time yet before she understood the extraordinary developmental route that Derek was charting for himself.

- **Adam Ockelford is Director of Rushton School and Children's Home for blind and partially sighted children with complex needs.**

RNIB runs a Music Advisory Service. For further information contact Sally Zimmermann on 020 7388 1266 or at sally.zimmermann@rnib.org.uk

In the Key of Genius is published by Hutchinson, £17.99 in hardback. Braille and audio versions available from RNIB, call 0845 702 3153 to order.

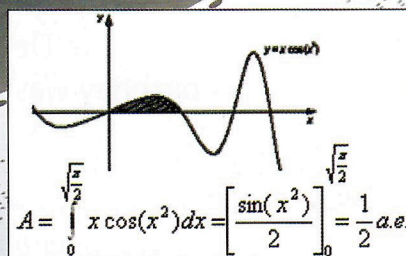


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