

Life with Lauren

An Odyssey Into Autism

Les de Villiers



Dedication

This book, in the words of Rabbi Isaac Mayer Wise, was conceived in sorrow, composed in grief, and constructed at the brink of despair. It contains “my mind’s best thoughts and my soul’s triumph over the powers of darkness.”

It is dedicated to all those kind people who accepted and assisted us and our daughter on this arduous journey. May it help other parents of autistic children to find their way through this abyss and may it also promote a better understanding and acceptance among those who chose to look the other way as we passed by.

I deeply appreciate Lew Bakes’ special input and advice in the process of writing this book and encouragement from, among others, Cliffe Knechtle, Matt Evans, Greg Zehner and Louis Luyt.

Above all, this book is dedicated to a wonderful wife who does so much to help our daughter and to strengthen me in times of despair and depression—and our son Andries who has been an understanding and caring sibling for his sister since his earliest childhood. It is, ultimately, Lauren’s book.

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About the Author

South African-born Les de Villiers moved to New York in the late seventies to become vice-chairman of a management consulting firm and subsequently established his own company. This followed a diplomatic career that involved negotiations with decision makers and heads of state in Africa, Europe and the United States. He has a doctorate in economic history and has written books about politics, business, conservation and travel, published in the United States, United Kingdom and South Africa. In his youth he also authored five detective novels in his mother tongue, Afrikaans. As an ardent wildlife photographer and conservationist, he takes time off from his publishing company every year to explore Africa—accompanied by his wife whenever she can break away from her real estate business. He also arranges safaris for clients. He is married to Ruth Steeves from Boston. They live in New Canaan and have two children, Lauren and Andries.



Lauren and her family in 1988



Lauren and her family on Thanksgiving 2010—joined on the right by Juliana, Andries' fiancée

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Foreword

She entered the world screaming at the top of her lungs. Today, at twenty-eight, she still giggles or shrieks with laughter and she cries sometimes. But she has never spoken a single intelligible word—except in her parents’ dreams.

Lauren’s is largely silent world—one in which she often seems shut off from everything around her. After a battery of tests and hours of observation the specialists came to some kind of consensus. According to them our daughter Lauren is autistic.

The term autism bespeaks our ignorance. It has become a convenient buzz word in a profession perplexed by a wide range of neurological and psychological aberrations. Consequently Lauren finds herself grouped not only with other nonverbal souls but also much higher functioning people whose only handicap happens to be a certain “odd” or “compulsive” behavior.

Yes, even those exceptional savants, who Hollywood likes to feature in movies such as *Rain Man*, are part of the mix.

Autism was first identified back in the early forties and was once considered an initial stage of schizophrenia. The name derives from the Greek word *autos* meaning “self” to depict the often withdrawn and self-focused perspective in people with the disorder.

Today the American Psychiatric Association recognizes autism as a pervasive developmental disorder. It is grouped together with Asperger Syndrome, Rett’s Syndrome, and Childhood Disintegrative Disorder as well as “pervasive developmental disorders not otherwise specified.” The

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latter is a convenient catchall category for children who clearly have impairments but don't meet the criteria for better known disorders. Often the differences between all these disorders are slight and confusing even to the professionals.

This book does not offer an in-depth study of autism. It is not a typical made-for-TV story with a happy ending either. There are no miracles here. Lauren is unlikely to wake up one morning and say “Mom” or “Dad” for the first time. She is coping with life as best she can—and so are we as her parents.

But some might view the transformation brought about by the birth of a damaged child like Lauren in our household as a kind of miracle by itself. Looking back we as parents can hardly believe all the fantastic—some might say miraculous—events that occurred during our difficult journey in the past twenty eight years.

While God has not chosen to bring sudden healing—despite our own prayers and those of many friends and fellow believers—He in his ultimate wisdom has used many strangers and nonbelievers to do wonderful things for our daughter and us. Their acts of kindness and compassion far outweigh the moments of deep despair and more than compensate for the hurt caused by a few unsympathetic persons that we have encountered along the way.

This book is for the vast majority of parents of a growing number of autistic children in America and abroad who, like us, have tried almost every new “miracle” cure that came along but never succeeded to pull their unfortunate children out of the abyss of autism.

In the early eighties when Lauren was born, Dr. Bernard Rimland put the incidence of autism at between 45 and 68 per 10,000 live births in the United States and the United Kingdom. At the time he expressed alarm at the

drastic increase of between 1,000 and 1,500 percent in the incidence of autism over two decades. Today experts put the chance of a baby in the United States being born with some form of autism at 1 in 150!

What is the reason for this dramatic increase? No one knows. What is clear, however, is that autism demands more public awareness, more understanding, and more funding, both private and public.

Autism is the most widely diagnosed developmental disability in the United States but receives only a minuscule fraction in research funds compared to the vast sums spent on childhood cancers, muscular dystrophy, juvenile diabetes, and cystic fibrosis—all of which together are less common than autism.

In the case of autism the probe for the causes and possible cures have been left to a few dedicated individuals like Bernard Rimland with limited resources and insufficient study data. It is evident that pinpointing the reasons for the alarming rise in autism among newborns in recent years is a necessary first step to prevention—which might prove easier than finding a cure.

Only a handful of the hundreds of thousands of autistic children yet to be born will recover sufficiently to function almost normally in society. Books will be written about some of these remarkable cases to be devoured by anxious parents hoping to find the key to unlocking the minds and souls of their unfortunate offspring. It might benefit a few but will leave most without any noticeable progress—and their parents frustrated and unfulfilled, even envious and bitter.

After their grandson was diagnosed as autistic, NBC Universal's CEO Bob Wright and his wife Suzanne embarked on a mission to learn all they could about autism and help ensure that their grandchild receives the best

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therapy available. Like the rest of us, the Wrights soon discovered how little we knew about the disability and how limited the resources for research were.

“Frankly, it’s been a difficult and frustrating challenge,” Wright conceded during an interview on NBC’s *Today* show. “We discovered, to our surprise, just how scarce the resources are for parents dealing with autism, and how thin the knowledge. We had so many questions, and instead of answers, we found a bewildering array of theories and guesses. We found it hard to believe that a disorder with the frequency of autism commands so little public attention and such meager resources devoted to research, compared to other, less common childhood disorders.”

Together with Home Depot cofounder Bernie Marcus the Wrights launched a campaign to promote an awareness of autism and recruit public and official support for meaningful research into its contributing causes. One can only hope that they succeed where others before them have failed. South African golfer Ernie Els, whose son has been diagnosed with autism, became involved. His golf bag carries, below his name, a promotion for *Autism Speaks*, the non-profit organization started by the Wrights.

For us as parents of Lauren there came a time where we have tried almost every known and new method or medicine to unlock our autistic daughter’s potential—with little or no noticeable progress. Being parents we will, of course, never give up trying. In the meantime, life must go on. We had to find a way to make daily living as meaningful and comfortable as possible for our child while living a life of our own. That is the greatest challenge facing parents of autistic children.

Even though this book has been written from the viewpoint of a couple who draw strength from their faith as Christians to cope with the challenges posed by our

daughter's condition, it is aimed at everyone who has to deal with autism: Jew, Christian, Muslim, Hindu, Buddhist, agnostic and atheist—men and women of all faiths and non-faiths.

It is the story of our odyssey into autism. If anyone learns anything from our experience in trying to cope with the enormous stresses and strains put on marriages and families by autism, this book will have served its purpose. If it prompts individuals, private organizations and governments to spend more time and money on research, it would be a special bonus. Hopefully, our story might help to pull parents away from self-pity and lead them into becoming strong advocates for their autistic children.

This is the story of our strikingly beautiful Lauren Elizabeth who lives in a silent world but who has brought us in touch with wonderful and caring people who gave us hope in the midst of ongoing pain. Perhaps, one day, these dedicated Samaritans will be joined by a nation willing to wage a war against one of America's and the world's most dreaded infant disorders.

Les de Villiers
New Canaan
Connecticut
January 2011



The first week



Smiling on Christmas Day



Cuddling up with Mom



Showing off in South Africa



With Dad and Joy, the house cat

1: *The Perfect Child*

Lauren Elizabeth de Villiers was born on Thursday, 24 June 1982, in New York's Beth Israel hospital. No Lamaze class could have prepared my wife Ruth or me for this event. No amount of rhythmic breathing and gentle handholding would have helped. I nearly crushed Ruth's hand while urging the obstetrician to do something to bring relief as she went into more than two hours of labor.

The doctor's solution was Demerol to kill the pain, Pitocin to speed up labor, and a pair of forceps clasped like tongs around our baby's head to maneuver her into this world.

Tears of relief spilled over my cheeks as the doctor clipped the umbilical cord and handed Lauren to the nurse to be cleaned, weighed and evaluated. A half hour later she rejoined us in a room which Ruth shared with another mother. All our well-laid plans to ensure a private room were to no avail as the birth came two weeks before the due date.

It all started during the afternoon of Wednesday, 23 June. Alarmed by Ruth's cries of agony I rushed to the bathroom of our midtown Manhattan apartment to find her crouched in pain under a running shower. I helped her to get dressed and summoned a cab while trying in vain to reach the obstetrician.

We headed for Beth Israel Hospital where she was placed in the care of the nurse who merely whispered words of encouragement while we waited to hear from the doctor.

Ruth wanted to get up and walk in a desperate attempt to relieve the pain in her abdomen and her swollen legs. The nurse kept holding her down.

2: *Into the Abyss*

In the spring of 1984, barely six months after we moved from New York City to New Canaan, construction on the new house started. With another child on the way, we felt that the time had come to expand our living space. Plans called for the construction of a four-bedroom Cape Dutch-gabled home on top of remnants of the original carriage house. Our builder—unfamiliar with this classic style that graces many a wine estate in South Africa’s Cape region—referred to it as “the Alamo in Connecticut.”

We had most of our furniture and belongings stashed away in a container on the property and retreated into a small downstairs bedroom as the heavy equipment rolled in to level the rest. We led a bunker existence for more than six months.

It was a season of growth. Ruth, the originator of the house plans, oversaw every facet of its development while nurturing new life in her own body. In the meantime, I tried as best I could to finish a new book in the midst of all this activity. One day I called my agent in the Midwest just as another pneumatic drill assault started on the rocky layer next to the living room. “Where are you calling from?” he shouted. “Beirut?” But no amount of noise or dust could spoil the joy of looking forward to a new house and a new arrival in our family.

So where did Lauren fit into all of this? At twenty months she was still not talking but we saw enough encouraging progress on other fronts to remain positive. She was walking. She was riding a tricycle with great dexterity. She smiled more often. When confined to her playpen with a stack of toys she made a game out of tossing them in different directions—chuckling with joy and with a sparkle in her eyes as we scurried about to pick them up.

Anyone who knows how to tease, I decided, had a lot going for her. It will not be long before she started telling jokes, I decided, but hopefully not that lame one about the broccoli.

One morning as I dropped Lauren off at Toddler Time in town a supervisor took me aside.

“I hope you don’t take this the wrong way,” she apologized, “but I do feel that I should let you know. Lauren does not seem to have much interest in what we are doing here. As a matter of fact, she is quite disruptive. Perhaps you want to look for an alternative program.”

“What you are saying,” I bristled, hardly able to mask the resentment in my voice, “is that Lauren is no longer welcome?”

“Well, if you want to put it that way, yes,” she replied.

I grabbed Lauren’s hand and led her back to the car—my anger manifesting itself in the abrupt manner with which I picked her up and strapped her into her seat in the back. She started crying. For several minutes I found myself driving aimlessly around town trying to calm her down while postponing the onerous task of sharing the bad news with Ruth. Eventually I headed out to the Silvermine area and turned into our property where I found Ruth in discussion with the builder. I took her by the hand and walked towards the river.

“Lauren’s in the car,” I fumed. “They don’t want her at the crèche any longer. Too much trouble, they say. Bastards!”

“I thought it might come to this,” Ruth responded in a trembling but surprisingly calm voice. “Who are we kidding? We have both known for some time that there is something wrong.”

lady behind the counter. “Will she play opposite Warren Beatty?” she asked with a serious frown while depositing the cash in her till.

As Lauren approached her fifth birthday our Norwalk neurologist suggested that we enlist Lauren for a special research program at the Albert Einstein College for Medicine in the Bronx. Heading this study of “autistic-like” children was the renowned expert, Dr. Isabelle Rapin. We were delighted by the prospect but Lauren was not impressed with Dr. Rapin’s credentials. She gave her no cooperation in what turned out to be an arduous experience for all involved.

In her report back to Norwalk Dr. Rapin apologized that she found herself “in the unfortunate position of having evaluated a severely handicapped child and not being able to come up with a definitive diagnosis.” She added, “I am not clearly able to say that she is autistic since she seems to be attentive to people in her environment [and] has a friendly smile.”

However, after a follow-up visit some time later, Dr. Rapin changed her mind. Lauren, she told us, is definitely autistic—without a doubt. By then we had already received the same diagnosis from other sources. Like other parents who had gone to many different specialists we discovered that diagnosing autism is not as easy and precise as diagnosing measles or a chromosomal defect such as Down syndrome. Autism is a neurological disorder that can only be diagnosed by observing a child’s behavior. Precise diagnosis by means of a blood test or brain scan is still not possible.

Replacing “static encephalopathy” with “autism” had little real meaning beyond providing us with a label that was easier to pronounce, albeit equally difficult to understand and explain.

LABELING LAUREN

With it came the shattering rider: Lauren's outlook for an independent life as an adult was zero.

While others continued to hold out hope, a near-retired psychiatrist at Yale University took it upon herself to break the bad news.

We were walking down the hall after yet another consultation with experts in the neurological disorder department of this hallowed institution when a matronly woman beckoned us into her smallish, cluttered office.

"Folks," she said, "I know we always want to hold out hope but I do feel that I owe you an honest opinion. Go home and think about how best you can prepare for Lauren's future. She will never be able to take care of herself, ever. She will most likely live for many years after you die. Think about it. Make your plans accordingly."

We walked out of Dr. Sally Provence's office stunned silent and sad—heartbroken, with excruciating pain eating at our insides. Between us Lauren was bouncing and shrieking with pleasure at the prospect of the drive home—tucked into her favorite seat in the back. She seemed completely unaware of the sorrow and the sadness around her.

All the way back to New Canaan Dr. Sally Provence's words kept spinning through my head and until this day I can picture her behind her desk and remember every single word. What she said seemed cruel at the time but I know she meant well. It took courage. Even though we might have resented her stinging bluntness at the time we realize today that she did us a favor.

Several years later I was intrigued to find Nobel laureate Pearl Buck relating an almost identical experience

in a little book about her daughter Carol who did not speak either and showed an uncanny similarity to our Lauren in many other ways. Written in the early fifties, *The Child That Never Grew* did not mention autism once but it certainly depicts all of our daughter's symptoms. Eventually Carol's mental retardation was ascribed to an inherited metabolic disease called *phenylketonuria* (PKU).

"Now came the moment for which I shall be grateful as long as I live," wrote Pearl Buck. She recounted how a little German-accented doctor stopped her along the passage as she came out of consultation with another physician and ushered her into his office.

"Did he tell you the child might be cured?" he demanded.

"He-he didn't say she could not," I stammered.

"Listen to what I tell you!" he commanded. "I tell you, Madame, the child can never be normal. Do not deceive yourself. You will wear out your life and beggar your family unless you give up hope and face the truth. She will never be well—do you hear me?...This child will be a burden on you all your life. Get ready to bear that burden. She will never be able to speak properly. She will never be able to read or write, she will never be more than about four years old, at best. Prepare yourself, Madame! Above all, do not let her absorb you. Find a place where she can be happy and leave her there and live your own life. I tell you the truth for your own sake."

"I don't know what I said or even if I said anything. I remember walking down the endless hall again alone with the child. I cannot describe my feelings. Anyone who has been through such moments will know, and those who have not cannot know, whatever words I might use. Perhaps the best way to put it is that I felt as though I were bleeding inwardly and desperately. The child, glad to be free, began capering and dancing, and when she saw my face twisted with weeping, she laughed....It was all a long time ago and yet it will never be over as long as I live. That hour is with me still."

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Pearl Buck died of lung cancer in March 1973, two months short of her eighty first birthday. Her daughter Carol remained for another twenty years in Vineland in New Jersey, where her mother had placed her after heeding the advice of the little German doctor. In 1992, she also succumbed to lung cancer. She was 72.

As Lauren approached her sixth birthday we faced the same challenge. We had agonizing decisions to make. If Lauren is to survive without us we had to start thinking about finding a place where she would be secure and safe. We had to ensure her well-being and financial security beyond our lives. But when do you start? When she is young and adaptable or much later when she is an adult and beyond control? How could one ever send a six year old away. How?

We have found a label called autism. But we had a problem that we never anticipated: A young girl who needed constant care for the rest of her living days. Our souls bled. As the days dragged on the pain persisted. I could see the sorrow in Ruth's cried out eyes at the dinner table while I tried unsuccessfully to mask my own agony behind a stoic façade.

Pearl Buck's words kept mulling through my troubled mind: "Anyone who has been through such moments will know, and those who have not cannot know, whatever words I might use..."