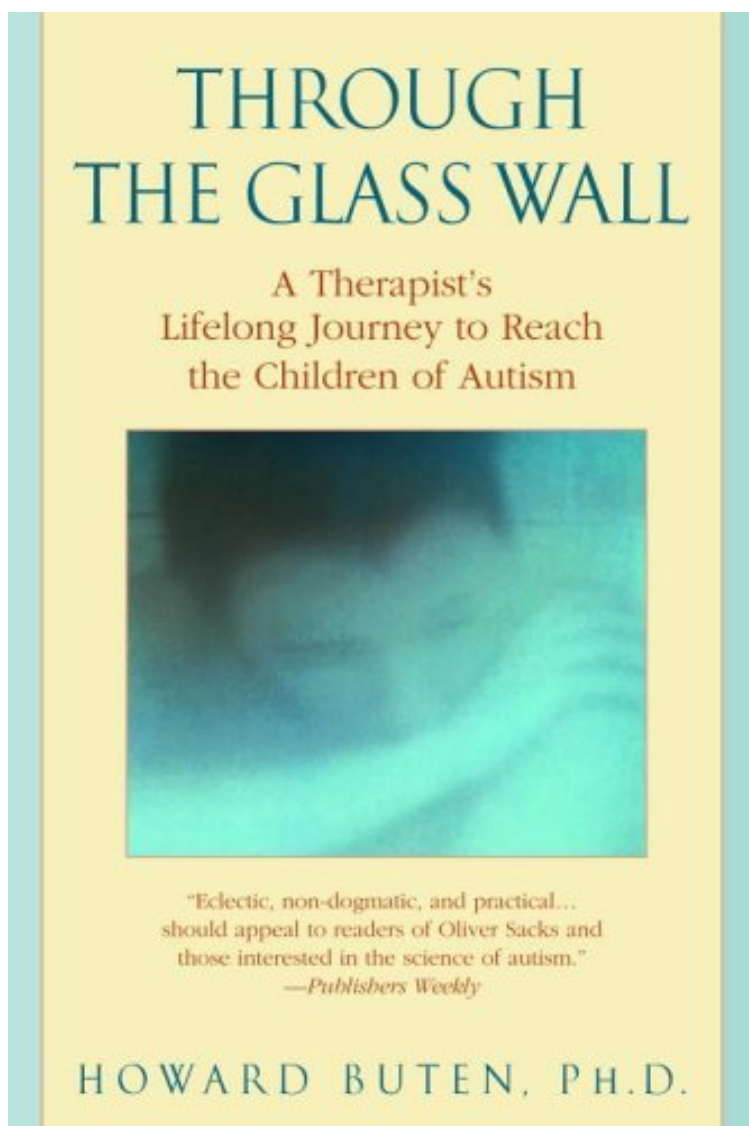


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Through the Glass Wall: A Therapist's Lifelong Journey to Reach the Children of Autism



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Description :

Prsentation de l'diteurA remarkable testament of hope and love, these pages recount Howard Butens lifelong journey working with autistic children. For three decades his pioneering, often controversial approaches have enabled him to gain access to their strange and solitary universea universe he shares in a book that is unlike any youve ever read. From his first unforgettable encounter with a wild, clawing human hurricane in the form of a little boy named Adam S., clinical psychologist Howard Buten has sought ways into the

seemingly closed world of the autistic child. Whether he's done this by letting himself be pummeled, scratched, and bitten, or by imitating the child's behaviors, or by feeling himself into what the child must be feeling, he has often been rewarded. With extraordinary insight and in ways that are powerfully moving, he brings to life as never before the innermost selves of these children. Among those you'll meet in the clinic he founded in Paris are Lise, whose seemingly random movements are as expressive as a dancer's; Florian, who can instantly tell you on which day of the week your birthday falls for any year, past or future; Martin, whose nonstop speech echoes the angry voices he has heard all around him, but who is impervious to the emotions they contain; and Hakim, a child so lost and so violent, no other institution will take him. Writing with a scientist's clarity and a humanist's heart, Buten conveys the reality of autism with passion, ruthlessness, humor, wisdom and love. This is a book both heartbreaking and hopeful, and when he succeeds in breaching the invisible wall of aloneness that seems to separate the autistic from the rest of us, we cheer.

From the Hardcover edition. Excerpt from *Hurricanes and Land Mines* I work with the autistic, in France. I founded an institution there, a day clinic dedicated to the treatment of extreme cases. I have always been most interested in extreme cases. When I was a child I wanted to be a doctor—I didn't want to become a doctor; I wanted to be a doctor, now! I'd found a copy of Morris's *Anatomy* in my cousin Bettie's attic when I was eight years old. I read the whole thing. There were lots of pictures. I memorized the appendectomy procedure—incision, artery, hemostat, suction, section, suture. I felt like a doctor. At the time I also felt like a ventriloquist; my mother had been a vaudeville performer in her youth, and she'd taught me to sing and dance, so ventriloquism seemed to be the natural next step. I taught myself the basics of the art with the help of a book entitled *So You Want to Be a Ventriloquist?* which I'd come across in the elementary school library while searching for a book that didn't exist but which would have been entitled, had it existed, *So You Want to Be a Brain Surgeon?* Inspired by these two parallel studies, I took to performing two or three appendectomies a week on my ventriloquist dummy (his appendix was a shoelace, inserted in his abdomen the night before, frequently inflamed). A year later my success, as well as that of Christiaan Barnard, allowed me to move on to open-heart surgery (a knotted maroon sock). Both my careers unfortunately came to an abrupt halt with the untimely demise of my dummy, who died of postoperative complications (falling apart at the seams) a few weeks before my tenth birthday. By the time I was twelve, I was already pursuing three "careers" at the same time: scientist, novelist and performing artist. I wrote my first novel at age twelve, and continued writing a new one every few years. Two years after the tragic death of my ventriloquist dummy, I as scientist won first prize at the Detroit Science Fair for my life-size papier-mâché "Visible Man." As a stage performer, I sang, I danced and I mimed; studied the violin (no talent), the trumpet (almost no talent), then the drums (talent). And by the time I was fourteen, I was spending the first half of my summer vacations as a volunteer in the pathology lab of a large teaching hospital in Detroit where my father knew somebody, cataloguing paraffin samples, carrying test tubes, looking into microscopes. Best of all, I got to wear a white coat, like Dr. Kildare. The second half of my summer vacations, I worked as a volunteer at various camps for various kinds of special children. I spent the first summer as a counselor's aide at the Michigan Muscular Dystrophy Camp. It was here that I perfected my peerless wheelchair-pushing technique: the continuous pushing down and pulling up on the handles from behind, the eye always on the next five yards, anticipating nooks and crannies and hills and dales—a human suspension system ever ready to ensure a smooth ride wherever your destination might take you. Over the years I worked with inner-city kids, underprivileged psychotic kids, "mongoloid" and retarded kids, inner-city underprivileged mongoloid psychotic kids. I learned the primal lesson of the ineffably narcissistic: doing good for others makes us feel good, the ultimate ego trip. One day, suffering from a broken heart and needing to feel good about myself, I took out the Yellow Pages and looked under R, for "Retarded." I thought I'd brush up on Down syndrome-kids so special that they're hardwired for kindness. I was referred to "Special Schools," and there I came across an address not far away. I called. I was given an appointment. I went. What I saw when I got there is why I'm writing this book.***It is 1974. I am twenty-four years old. I am sitting alone in the waiting room of the Children's Orthogenic Center in Detroit, wondering what "orthogenic" means. Suddenly the room is deluged by a hurricane. The hurricane comes in the form of a boy, bursting through the door, throwing himself to the floor, sitting up suddenly, legs out straight and back stiff, rocking back and forth, hands in his lap, eyes staring into middle space, his hoarse voice spitting out syllables as if he'd swallowed something, but hadn't. I have never seen anything like this before in my life. It is stunning. I am stunned . . . and somehow delighted. At twenty-four it is already rare to suddenly see something one has never seen before in one's life. My immediate instinct is to fall on the floor and do as he is doing. I want to know what in the

world it could possibly feel like to be him. I didn't know at the time that this was to be the most burning unanswerable question of my life. "Extreme cases" may be defined in several ways. One might describe an autistic person who is particularly violent, one who bites, scratches, slaps, spits, bludgeons the people around him-caregivers, family members, other patients-and himself. The term might also apply to those autistics whose pathology makes them extremely hard to get through to (by definition, if you're autistic you're hard to get through to): inert, retarded, difficult to motivate, impossible to move. Or it might also refer to a person who has an extreme effect on the family or on the institutional staff: someone who may be neither violent nor inert, but whose behavior is so disturbing, disruptive or obnoxious that the weight of his or her presence pushes us to extremes. It was an extreme case that initiated me into my profession, that day in 1974. The hurricane's name was Adam S. He was four years old. I was to learn later that of the twenty-five-odd youngsters of the Children's Orthogenic Center (orthogenic may be defined as for the care and education of children with emotional or cognitive disturbances), Adam S. was the most difficult, the most dangerous. He bit. He bit and he head-butted and he pinched and he pounded, himself as well as others. He had no language. He did not come when called. He would not sit still in a chair. He would sit on the floor at length, however, rocking back and forth, tapping his head backward against the wall; I can still see the bald spot where he'd worn the hair away, a small tempest-tossed island of scalp in a turbulent afro sea. Adam threw fits. Suddenly, for no apparent reason, he would hurl himself to the ground, flailing his arms, churning his legs, hitting his forehead against whatever surface he found himself on, rolling across it, beside himself, a banshee. We would try to subdue him; it usually took three or four of us. Sometimes we put him in the timeout room; sometimes we'd stand there, impotent, waiting for the storm to pass. Adam, autistic, was invulnerable to everything, including pain. I once watched him climb a hurricane fence, slip and fall to the ground five feet below, flat on his back, then pick himself up and walk off without so much as a whimper. It eventually dawned on me that the boy had an extraordinarily high threshold for pain. (Certain studies in the 1980s were to demonstrate that some autistic people have elevated levels of substances called endogenous opiates-endogenous means made by the body itself-that act as natural painkillers; one of those opiates is beta-endorphin. This finding would also help to explain these people's self-injurious behavior: living in a state of perpetual semi-numbness, they could be driven to self-mutilation in an unconscious effort to feel themselves.) I reasoned that if it was true that Adam did not feel pain as you or I do, he would understandably have trouble distinguishing a caress from a scratch, a friendly slap on the back from a punch in the nose. This had to be explained to him. But how? Given his low level of verbal comprehension, what could we do to make him understand the difference? An act of aggression inflicted by someone who does not distinguish violence from tenderness is aggressive only if the person receiving it experiences it as such. If a coconut falls on my head but, thanks to the football helmet that I always wear, doesn't hurt me, no aggression or violence exists; the coconut didn't fall on me on purpose, and I experienced nothing unpleasant. I decided to create a microcosm wherein Adam's violence would simply not be experienced as such, and thus would not exist. During the summer, the Children's Orthogenic Center was closed for classes, but the building stayed open for consultations. We decided on one-hour sessions, three days a week. I chose a small empty office which was rarely used, with one small window and carpeting on the floor. In the beginning I spent most of my time dodging Adam's teeth, fingernails and fists. I learned to do this calmly, through minimal, fluid movements, a kind of Aikido invented for the occasion. I showed no signs of panic, stress or unpleasantness. What I couldn't avoid I simply took, stoically, betraying no reaction whatsoever, practicing a sort of self-hypnosis that renders one invulnerable to pain-or, rather, invulnerable to the slightest reaction to pain; enabled, I suppose, by some primitive survival instinct as well as an extremely self-indulgent Zorro complex. This aside, I spent most of my time imitating Adam, mirroring him: rocking when he rocked, flapping my hands when he flapped his hands, screaming and humming when he screamed and hummed. We crossed our eyes at the same time, flung ourselves against the walls as one, bit ourselves on the hand together, banged our heads in sync. Outside the little room, Adam followed me everywhere, came when I called, did whatever I asked. My colleagues were dumbfounded. Time marched on. It is early August. Adam and I are in session. Adam is standing there in the corner of the little room, making his favorite noise, "sih-sih-sih." (This afternoon's program will also include "Ah-um, ah-um, ah-um UM!" as well as the ever popular "Tik-a-tik-a-tik.") I sing along, standing in the opposite corner. I realize again how pleasant it is to ...Revue de presse"[Buten's] approach to autism is eclectic, nondogmatic and practical: if it works, he does it. ... Imaginative play, humor and inventiveness sparked unexpected breakthroughs."--Publishers

Weekly From the Hardcover edition.