## Mark Osteen

# The Play of Shadows

I have a little shadow that goes in and out with me And what can be the use of him is more than I can see He is very, very like me from the heels up to the head, And I see him jump before me when I jump into my bed....

He hasn't got a notion of how children ought to play And can only make a fool of me in every sort of way...

- Robert Louis Stevenson, "My Shadow"

boy's room is a snapshot of his life and loves. The picture changes as he grows and gains new interests. And so my baseball cards and battered glove gave way to a stereo, Beatles posters and orange paisley wall hangings.



My son Cameron's room also reveals his nature, as I discover one day when David, a stocky man from Disability Services, visits to determine whether Cam, who has autism, qualifies for assistance. As we enter my son's bedroom, I suddenly see the room through a stranger's eyes.

"Wow, look at all the toys," David comments.

A plastic Fisher-Price basketball hoop and backboard lean against the closet. A silver portable Sony CD player sits on the white nightstand; inside, CDs are piled helter-skelter, mixed with a heap of mutilated toddler books—Good Night Moon, The Runaway Bunny, Max's Christmas.

Assorted children's videos — Raffi in Concert, Disney singalongs (The Bare Necessities, You Can Fly), numerous

Kidsongs tapes—spill over the top of a blue plastic trash basket; some lie on the floor. Beside the twin bed rests a giant blue therapy ball. Beneath the window, a hulking trunk is packed with colorful toys—three different toy guitars, a "Magic Lights" keyboard, an unused baseball glove, two kid-sized basketballs, a Pinpressions novelty, a little boy's pounding bench. There are no other books, no video games, craft supplies or soiled jerseys.

"How old did you say Cameron is?" David asks.

"Eleven."

I open the closet. Here lie the remains of six years of Applied Behavioral Analysis therapy: bins of colored objects shine into the darkness; twelvepiece puzzles, certain pieces chewed, are stacked unevenly on an aluminum book shelf; above them, a Mr. Potato Head—nose twisted, tongue protruding, one arm gnawed to a stump—stares blankly. On the top shelf reposes a snazzy maroon bicycle helmet, its dark brown flames running front to back.

Both of us remark the room's most striking feature: stark white walls, which bear no garish hangings, no posters of pop stars or athletes. They bespeak a bare imagination, telling of a boy who doesn't have heroes because he doesn't imagine being anyone else.

This is the room of a boy who doesn't play.

In this regard, Cam is typical – of people with autism, at least – because the absence of imaginative play is one of the disorder's three distinguishing features. At first this may not seem as debilitating as, say, the inability to speak, but actually it may be worse. For one thing, as Clara Claiborne Park points out, an incapacity to play imaginatively seems to violate a fundamental human trait (265). No play means no curiosity, and hence no science, no literature, no exploration, no empathy – none of that vital elan that has raised humans from the mire. More concretely, the inability to play prevents autistic children from developing problem-solving skills, learning social cues, and hewing out the building blocks of other cognitive processes. Because play is, as Bryna Siegel puts it, the child's laboratory "for conducting 'experiments' on the things around him," a child who can't play doesn't discover novelties, expand his reach or learn from mistakes. Thus, Siegel writes, "teaching a child with autism how to 'play' is tantamount to teaching the child . . . how to learn" (236, 238).

As I explain to David, one of the main goals of our ABA program (a form of modified behavioral training) is to teach our son to play and imitate others. Under precise and limited circumstances, Cam has learned to imitate certain gestures and facial expressions, but the larger goal—inducing him to

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interact with others – has remained elusive.

I tell David how Cam learned the "Perfection" game (a matching exercise) well enough to match every one of its thirty squares to identical icons. I recall

how my wife Leslie and I watched with delight as Cam mastered a toy cash register, amusement park, and Fisher Price car garage. But his mastery lacked creativity: he never pretended to hand out change or made those growly auto noises most boys can produce. His play remained as mechanical as the toys. He rarely

used the skills outside of sessions, and novelty prompted resistance or downright hostility.

David assures me that my son qualifies for services. After he leaves, I finger the objects in Cam's room, each one embodying a failed attempt to spark his imagination. It is hard not to see them as monuments to dashed hopes. Then I realize that they are better seen as a material record of our relationship.

#### CHORDS LOST AND FOUND

As a kid, whenever I wasn't reading, I was doing one of three things: playing or listening to music, riding my bike, or playing baseball. Our family was musical: my dad had a long-term country band, my mother sang in a well-regarded gospel trio, and they owned tons of records. I started piano lessons at age eight and have performed profession-

ally throughout my adulthood.

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Naturally, I pounced on any signs of musical interest in my son. They weren't hard to find. By age two he was obsessed with his music cassettes (everything from *Peter and the Wolf* to

Pete Seeger) and singalong videos. A favorite was "This Old Man." Thank God for the old geezer! In moments of severe stress - at the dentist's office, waiting at the grocery checkout Les and I could break into the song and Cam, no matter how upset and seemingly beyond reach, would join in-"This old man came . . ." "Roan-

ing hone!"—and instantly calm down.

"If I See an Elephant Fly," from *Dumbo*, "I've Got No Strings on Me," from *Pinocchio*, and Raffi's "Baby Beluga," and "Down by the Bay" – these have been the soundtrack of our life with autism. When Cam first started watching the Raffi videos, the children in the video audience were older than he; they stayed the same as he grew larger. To my wife and me – and perhaps to Cam himself – Raffi represents the earlier, happier years when Cam's cognition and senses were less disordered.

Favorites also emerged among the Disney videos, mostly exuberant tunes like "Mr. Toad's Wild Ride" (with its "merrily, merrily, merrily"chorus), "Supercalifragilisticexpiali-docious," and "The Unbirthday Song." The films themselves bored Cam, but *Pinocchio* 

and Dumbo carried a special poignance for his parents. We wondered: did Cam see himself in the gullible marionette who longs to be a real boy? Did our nearly wordless son feel like Dumbo, oppressed by muteness and shunned for his difference? Was his apparent

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lack of interest in the stories actually revulsion at witnessing his own disabilities portrayed?

He did watch one movie all the way through: Mary Poppins. And he watched it every night. I mean every night. If we tried to interest him in a different film, he

vehemently insisted on "Poppins." It's a great movie. Even so, after the fivehundredth time, I knew that if I heard "A Spoonful of Sugar" one more time I'd definitely upchuck.

It seemed plausible that Cam might want to play an instrument. When he was about six, I laboriously taught him a one-finger version of "Twinkle, Twinkle, Little Star" on the piano. I'd pull out his index finger (he couldn't point on his own) and strike the first note. We'd pound away roughly, my hand moving his reluctant pointer to the C, the G, the A, and so on. By the time we struck the last "are" he'd be squirming.

"Good playing, Cam! Want to play something else?" But he'd already be bouncing on his little trampoline. Whenever I tried to show him a different tune, he requested "Twinkle, Twinkle," and if I persisted, he'd pinch me or flee. Once I bought a programmable electronic keyboard with keys that lit up to show melodies; it lit no spark in Cam.

At about age ten, he became fascinated with simple electronic musical toys. We bought every one we could find, and he soon progressed from

> one-button toys to and keyboards. So what if the toys were designed for kids half his age – our son was playing!

> We really hit the jackpot with a "Blue's Clues" radio, a tiny toy with buttons that played six songs from the TV show. Cam had

complicated guitars

never watched Blue's Clues, but that didn't matter. What mattered was that a) he liked the songs; b) he could play an entire short tune just by pressing one button; and c) he could *choose* which one to play. There was a birthday song and a mail-time song, but our number one hit was the Solar System Song: "Well, the sun's a hot star / Mercury's hot too / Venus is the brightest planet / Earth's home to me and you," and so on, all the way out to Pluto. For a couple of months the toy was Cam's own satellite, perpetually orbiting at arm's length.

On a Saturday visit to the grocery store, Les and I discussed lunch meat while our son, Blue's Clues radio clutched in his hand, slipped away. For fifteen seconds neither of us noticed his absence. When we did, we fanned out in search of the lost boy.

I listened intently for his telltale laughing or shrieks. Instead, from a

FALL 2009 87 couple of aisles over, I heard, "Well, the sun's a hot star / Mercury's hot, too / Venus is the brightest planet / Earth's home to me and you. . . ." He was in the soda aisle, his right hand gripping a large bottle of cherry seltzer, his left hand grasping his radio, chin turned to the ceiling, giggling and spinning wildly. Two middle-aged ladies gaped,

shoulders hunched, afraid to approach the whirling body.

A few weeks later he threw the toy down and never picked it up again.

When Cam was about nine, my mother bought him a harmonica for Christmas. This was better than a piano: you didn't need

fingers, didn't need Dad's help. You just breathed and notes came out. For a few weeks, the first thing he did upon waking was pick up the "'monica" and blow a lusty "wheee – heee." After a couple of huffs he'd eagerly turn to me for approval.

"Good blowing, Cam! That's excellent!" He'd smile, sway and clap his hands for punctuation.

We began presenting the harmonica as an activity and reward in the ABA program. But as soon as play became work, the harmonica was contaminated. He soon abandoned it. Another failed experiment.

But one day months later, after rummaging through the kitchen drawer where we kept stray toys, Cam pulled out the harmonica. He put it to his lips and blew a loud chord.

"I sound good," he announced, shoving it back into the drawer.

He believed he'd mastered the instrument. So why continue?

### THE CYCLE CYCLE

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As a tyke Cam loved riding in his stroller: he seemed to feel both liberated and protected when he had wheels. When he was six, the staff at his school told us he'd been riding a large tri-

cycle at recess, so that Christmas we bought him an expensive black bike, complete with hand brake and training wheels. In the months that followed we frequently took Cam and the bike out to the road next to our house. While I walked beside him, Les stationed

herself fifty yards away, where the road reached a dead end.

"Cam! Ride to mommy!" she shouted.

As I held the bike Cam carefully placed himself on the seat and stared down at the pedals. "Look where you're going, buddy, not at the pedals!" I pointed to his mom up the road. His head snapped up. But then he forgot to pedal.

I pulled the handlebars. "Come on, let's go fast!" He pedaled tentatively. I gave him frequent pushes until we reached his waiting mom. "Way to go, Cam!" she'd shout, giving him a big hug. "You are so talented!"

Then we'd turn him around — making sure to keep him on the bike so he wouldn't get distracted by the weeds at the edge of the pavement, or the smell of his mother's hair, and forget all about riding.

Within a month or so he could ride the two blocks to the dead-end without crashing. The bike had replaced Cam's beloved stroller—literally: whenever he wanted to ride, he'd shout, "'troller!"

We were overjoyed: for once his abilities and interests were age-appropriate. But this budding skill also presented a problem: our son could ride at a rapid clip, but lacked all sense of danger, and the return trip from the dead-end was all downhill. That meant he could pedal faster than I could run. And although I'd shown him countless times how to brake, he could never remember how to do it when he needed to. Running behind him, I'd yell, "Cam, use the brake!" Thighs aching and heart thumping, I'd grab the handlebars, often just as he was about to slam into the curb or a parked car.

Once I slipped and he rode away. As our son streaked down the middle of the street, Les and I stood, shoulders raised, teeth clenched, braced for the imminent crash. Then we shook off our stupor.

"Buddy!" she shouted, sprinting past me.

Luckily, the road runs uphill for thirty yards past our house, so gradually the bike slowed down, permitting Les to block it and halt our flushcheeked son.

After some months, however, he stopped requesting "'troller." Maybe he was frustrated that he couldn't get beyond the rudiments: a year after we'd started, he still needed training wheels and couldn't consistently steer or stop. Or maybe the whole exercise seemed pointless, for Cam seemed to have no notion that the bike could take him places. And, frankly, we didn't want him to. If he left our sight, there was no telling what might occur. With a

shudder I banished intrusive images of broken body and twisted bike.

One day during the Late Bicycle Period, Cam's feet slipped from the pedals as he glided down the hill in front of our house. "Turn left! Turn left!" I shouted.

The black bike slowed, swung sharply left, and collapsed in a heap. Cam fell off, striking his penis on the seat. I ran to where he sprawled on the asphalt. "Doodle man! Are you okay?" He growled and slapped at my shoulder.

Ever after, the bike was toxic: at best he'd make a few half-hearted pedals, then leap off and let it collapse. He had learned an important fact: you could get hurt on that thing. By '98 we'd given it away.

That Christmas, after disdainfully surveying the presents under the tree, Cam started growling and slapping his chest. After several minutes of agitated vocalizing, he turned to Leslie and said, "Stroller?"

We exchanged mystified looks. Cam clarified: "I need a present."

Somewhere he had heard that boys got bikes for Christmas. Clearly we were depriving our child of the one thing he really wanted. That week we bought him a new bike. He wouldn't even get on it.

Thus ended the cycle cycle.

#### STRIKE THREE

My sister and I grew up in a kidfilled neighborhood in western Montana where two vacant lots served as ball fields. Whenever our gang wasn't playing baseball, I conducted imaginary games in the backyard. For hours on end I'd hit and catch fungoes, or sling the ball against the shed while pretending to be a major-leaguer. I idol-

ized ballplayers and collected hundreds of baseball cards, which I pored over, categorized, stacked and filed daily. I knew every player's stats by heart, and wowed adults with this arcane knowledge.

When Cam was five, I bought him a wiffle tee-ball set up.

"Okay, Cambo, let's hit the ball. Like this."

I put his hands on the bat, placed my hands over his, pulled back the bat and took a healthy hack.

"Now you do it."

He dropped the bat and ran away. I coaxed him to try again, this time keeping my hands on his as we walloped the wiffle ball.

"Wow! What a hit! Now run!" He had no trouble with that part, and generally sprinted toward the neighbors' woods.

The game may have seemed absurd to him: you run around to where you started, and then begin again. So why run? The notion of competing and winning was either beyond him – perhaps because it demanded that he imagine somebody else's thoughts – or seemed silly. Besides, he had his *own* rules: outside is for swinging or stripping the leaves from trees. Everything else is

I desperately wanted Cam to succeed at this, so the next two springs and summers we worked on hitting. He learned to hit a pitched wiffle ball pretty well for an autistic boy, but he never really wanted to hit the ball. I persisted anyway, and when Cam was nine enrolled him in a Challenger League for disabled kids.

At the first practice we waited for the coaches to get organized, which allowed ample time for Cam to move from first base (reluctant cooperation) to second base - wandering away, sit-

> ting down, plucking grass.

> 'Okay, let's hit the ball," I said, steering him toward the line forming near the batter's box.

"Huh-uh-huhuh-huh-uh." He twisted his t-shirt ing my knuckles with his nails.

Les questioned me with

into a ball and gnawed on it, meanwhile goug-

her eyes: is this worth it? I ignored her, then watched the other kids - Down syndrome girls and boys, kids with CP—whiff or feebly tap the ball. My kid could do better than that. But by the time Cam's turn to bat arrived, he'd already reached third base: angry defiance. Slumping to his knees in the muddy batter's box, he slapped the ground and growled. He refused to get up.

Red-faced, I implored, "Come on, buddy, I know you can do it. Don't you want to hit the ball? It's fun!"

"This is not working," Les said. "Let's just try it one more time." "Mark. Think. This is ridiculous. Somebody's going to get hurt."



Cam with his dad.

I stood, arms akimbo, a petulant ten-year-old whose mother has called him home from a game. Cam grabbed my t-shirt, ripped it, then sprang up and loped toward the car. Glaring at his back, I trudged in his wake. My kid had made a scene again. Christ, he couldn't even hold his own with other disabled kids.

Cam sensed my intense desire for

him to succeed, which burdened the game with expectations he couldn't (or didn't want to) fulfill. From then on, he went on a sitdown strike or ran off as soon as I picked up the bat. In fact, swinging the wiffle bat became a surefire way to get him into the house. I kept trying until one day, as I was chas-

ing him around the yard, I suddenly myself as one of those sports-crazed dads who hounds his kid to live out his own dreams. I could almost hear myself shout, "Have fun, damn it!"

#### A Boy's Best Friend

Both Les and I came from dog families. Her family had two beagles, then an unruly Chesapeake; we owned a fidgety little mutt named Snooky, then a Lab-Irish Setter cross that my golf-besotted father named (against our vehement protests) Par. Snooky often followed me partway to school, barking as she turned back as if to remind me to keep my shoes tied and nose blown.

Would a dog serve as companion for our solitary son? In theory, maybe;

but Cam didn't trust the noisy, wiggly, smelly creatures. By the time he was seven or eight we could coax him to approach the neighbors' greyhounds and gingerly touch their coats. But even that mild interest ended on a November Saturday in 1999, when Cam was ten.

As Cam foraged around the yard, a neighbor boy came by with two small, energetic black and tan mongrels. Spot-

ting my son, the dogs began barking fiercely, then jerked free of their leashes and charged. Cam's loping gait made him an easy target for the lead dog, who nipped at his shoes and legs as if he were an arrant sheep.

"Eeehhh!" he screamed, running in a circle and raising his arms as if

trying to take flight.

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Stupefied, I stood staring for several seconds before dashing down the hill to chase the dog away. I scolded the kid, sent him home, then examined my son. The dog had bitten through Cam's jeans in two spots, but I didn't see any marks on his skin. No big deal: a near miss.

When I returned from the bookstore an hour and a half later, the situation had changed dramatically.

Actually the dog *had* broken Cam's skin. Les had called animal control; they'd urged her to phone the police. A policeman had visited and told her to contact the owner, a neighbor we'd never met.

"Hello. This is Leslie, from down the street."

"Oh, hello."

"I need to tell you that one of your dogs bit my son." She provided the details.

"Our dogs don't bite. Your son must have teased him."

"My son is autistic and mentally disabled. He isn't capable of teasing a dog." Her voice grew tight. "He was minding his own business, when your

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dog got away from the boy who was walking it and bit my son."

"The boy wasn't supposed to be walking the dog. Anyway, my dog wouldn't bite."

"Let me be clear: your dog attacked my handicapped son while he was playing in his own yard." Her forced friendliness had vanished.

"Oh, the dog might have snapped at him. That's how we play with them: we get them to snap at toys."

Silence.

"Well, I guess it's hard to understand."

"All I know is that your dog bit my son. We need to know if his rabies shots are up to date. We'd appreciate it if you'd check on that. We'll call you tomorrow."

It turned out that the animal's shots were not up to date, which meant he had to be quarantined for ten days. If rabid, he'd be destroyed and Cam would have to undergo a series of painful shots. I grimaced as I envisioned a long needle jabbing his stomach.

During the quarantine I battled guilt. I should have watched Cam more closely. I should have been trying to play with him instead of letting him run wild in the yard. I should have sensed danger and put myself between the dogs and my son. If Cam got rabies, I would never, ever forgive myself.

Fortunately, the dog was not rabid. But Cam now won't go near dogs.

Cam's best friend was not canine but a human—another autistic boy named

Andrew. I witnessed the friendship's birth one morning a few months later, when a slender boy with curly brown hair and sparkling dark eyes began to follow my son around. When Cam got on the slide, Andrew got on the slide; when Cam clapped, Andrew clapped; when Cam jumped on the tramp, Andrew jumped on

the tramp. He was Cam's shadow.

Soon the boys became inseparable at school. Outside of school, however, the relationship was hard to sustain. Our attempts to bring them together seemed jinxed. Once Andrew's parents invited us to the Laurel racetrack for Andrew's birthday party. But an ice storm struck that day, making the forty-five minute drive too hazardous. Over the next few months, whenever we tried to arrange a play date, Andrew's parents wouldn't commit, or one of the boys got sick.

The next year Cam moved up to middle school, leaving Andrew behind. The friendship withered.

About a year later, as we were finishing a gymnastics lesson, Andrew unexpectedly walked through the door of the small cool-down gym. "Hey, Cam. It's Andrew. Hi, Andrew!" I said.

Andrew emitted a high-pitched squeal and trotted up to Cam. The boys exchanged double high-fives, clasped hands, touched foreheads. Andrew squealed again; Cam broke into giggles.

The pals had missed each other. I'd never before seen my son

acknowledge another child, let alone interact with one. Cam had been swinging in the middle of the room; now he gave up his seat for Andrew.

On the drive home that day I grew angry at the school all over again for separating the boys. Had they even consid-

ered the friendship's positive effects on the kids before they'd made the change? No. Cam had reached the age to move, so they moved him.

Still, the relationship mystified me. Other boys bond over skateboards, video games, card collections. But Cam and Andrew – both autistically self-involved – could hardly share interests. Did they recognize their common disability? Did my son, a head taller and 15 pounds heavier, protect Andrew? Did Andrew, with greater initiative and fewer problem behaviors, watch out for Cam? Was some mentor-protege relationship taking place?

The scene at the gym had showed that, like other boys their age who hit each other, make fart sounds with their hands or pull goofy faces, these two didn't need words to communicate. They enjoyed each other's company. They might have been friends even if they hadn't shared a disorder.

Why, then, hadn't we done more to encourage this friendship? Maybe we simply couldn't believe that our son, who had always ignored other kids or treated them as nuisances, really had a buddy, a mirror in whom he could see

and define himself. But perhaps there was another reason.

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ME AND MY SHADOW
Les and I wanted Cam to learn
to play so he'd
have something to
share with others.
We wanted him to
have the kind of experiences that had
defined our child-

hoods. But I didn't merely want my son to play; I wanted him to play with me. I wanted him to respond to my coaching, to pedal beside me while I warned him about dogs and traffic lights. I wanted him to be my shadow. He wanted to be someone else.

We've played two games together successfully, and neither carries memories from my childhood. When I cared less, he cared more.

One is hide-and-seek. In our version, I tickle Cam, then crouch behind a door. "Where's Daddy?" I ask. His eyes sparkling, his mouth twisted into the lopsided grin that means he's expecting something uproarious, he trots toward my voice, stopping every two feet to giggle. I growl, pounce, tickle his ribs. Cam semi-resists, then flees or collapses in laughter.

No cargo of expectations weighs us



Cam with his dad.

down. But no sign of this game lingers in his room. It exists only in memories of glee.

One evening when our son was driving us bonkers—running through the house, pounding on the floor and walls, shouting himself hoarse, giggling incessantly, burping compulsively—I banished my worn-out wife to our bedroom and coaxed Cam into playing basketball.

Hoops has always made sense to him: you just put the ball into the basket. Usually I take a shot, yell "Two points!", then, "Cam's turn." During my shot he lies on the bed, bounces on the tramp, or stares out the window, but at his turn he usually gives a good effort.

Over the years I'd taught him a simplified version of "HORSE," which I named "ABC." I shoot from the center, then he shoots from the spot: A. We move to one side for B, and to the other for C. I have to prompt him to take each shot and praise him profusely for each one made. Occasionally he gets really excited and shouts, "two points!" If he misses two or three in a row, he'll chew his shirt or bite the ball - he wants to win.

On this evening he was even less compliant than

usual. But a challenge drew his interest.

"Cam, stand over here by the night stand. Try to throw it in from here!" He walked to the far end of the room, took aim, and missed. Twice. Growling and chewing commenced.

"Buddy, you can do it. Take your time and try again!" He took aim and sank it.

"Yay, two points for Cam!" We slapped five—any father and son shooting hoops at home.

The struggle to teach my son to play was a prism refracting my own child-hood—of days spent devising solitary games with private rules, of conjuring a second self who called play by play and

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drove me to excel. When Cam came along, I tried to make *him* my shadow. Only when I turned down the spotlight of my hopes and dreams did I glimpse the boy my shadow hid.

Yet Cam also has a second self. It emerges whenever a bright light shines at the proper angle, and he stops whatever he's doing to create shadows on the table, wall or door. It's as if he's talking in sign language to some unseen interlocutor. His hands, usually so maladroit, suddenly acquire grace and elegance. Yet he seems both surprised and gratified by these shadows, as if he both knows and doesn't know that he has made them. Perhaps the shapes appear to him as abstract art, all chiaroscuro and contrast, each one pure and self-contained – from him, yet not of him. The shadow moves when he does, yet changes unpredictably - one minute small and helpless, the next large and menacing — a companion whose actions mirror his own. Perhaps the shadow world, peeping from behind the blinds of his perception, appeals to him as a sign from some other world — the elusive home, that place where he truly belongs. Or maybe the shadow self assures him that he is, indeed, truly and only himself.

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