

Dispatches
from
Ray's Planet

A Journey through Autism

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CAITLIN PRESS 2020

For Writing Man



THE GAME

Goongbalong. That is the word Ray invented to describe the game that humans play among themselves. It's the game of tact, social niceties, subtle hints, little white lies, polite chit-chat—manoeuvres that have eluded him all his life. To him, those things amount to a lot of people working very hard to *not* say what they mean.

It's not only master manipulators who play the game—we all do. Anyone who says, “Are you *sure* you can't stay for dinner?” when she's grateful you're leaving and hopes never to see you again is making a nice *Goongbalong* pass. Anyone who pretends he doesn't notice the wart on your nose or your “lazy eye” is playing just a little.

The rules of *Goongbalong*—or “The Rules,” as Ray calls them, always with air quotes for emphasis—are unwritten, and yet somehow everybody else seems to know them. The consequences of flouting them are swift and severe. Ray spells it out to me in an email:

There is a certain kind of person—a woman, usually—who can come to hate me so much that they seem to be on the brink of insanity. It would be a Great Moment in my life if I could come to understand why this happens. This hatred can, on occasion, blossom almost instantaneously. I commit some *Goongbalong* foul that seems to entail absolute and permanent expulsion from that person's social circle. It can happen anywhere, anytime, which is why I'm in a state of constant terror when I'm around other people.

Constant terror? Ray's use of such a potent phrase takes me aback. We grew up in the same house, and I, only sixteen months his junior, have never detected a mote of fear in him. I always thought of him as, if anything, a little overconfident.

“Surely you’re just being paranoid, Ray,” I write back. “It can’t be that bad!”

But Ray, who insists on using my long-obsolete childhood nickname, assures me that it is:

Yes, Babs, it’s that bad. Some of them have erupted in spitting, stuttering, purple-faced rage. One example was my dentist’s receptionist back in West Van. I only saw her once every six months—and that was at the beginning and end of my appointments. For the love of God! How much did we have to do with each other?? What on earth could one say to a receptionist to piss her off to such a degree?

Ray answers his own question:

I didn’t really “do” anything; I just emit the wrong magnetic field or something. I’m mostly always terrified and maybe people can smell fear the way a dog can. Maybe fear smells like arrogance.

And unfortunately, there’s no opting out:

You are not permitted to sit out the game—you **are** playing all the time, whether you like it or not.

Goongbalong. It doesn’t roll easily off the tongue. And that’s just the way Ray wants it: it’s hard to say because it’s hard to play. “Every time someone has to pronounce my word,” he tells me, “they are forced to do something unnatural and counterintuitive. That’s my life. My word is my revenge.”



Ray just couldn’t seem to learn The Rules—even though they came factory installed in the rest of us. As he grew into a teenager, many people concluded that he was simply too arrogant to toe the line. They said that a guy as smart as he is could easily fall into step with the rest of us if he wanted to, but he preferred to make some sort of “statement” by

thumbing his nose at accepted standards of behaviour, always looking for a way to distinguish himself from the herd. “Well, that’s Raymond, isn’t it, dear?” said our Aunt Nell when he turned up at a family party in greasy coveralls with grime under his nails. “He just *has* to be different.” And maybe there’s some truth to that: Ray is not interested in blending in. But given what I now believe to be the case, it seems to me that he never had as much choice in the matter as everyone thought. Including him.

Ray has always known he’s different, but at sixty-three years of age, he certainly doesn’t believe he needs to be cured. According to him, the world would be vastly improved if everybody thought and behaved the way he does. He embraces the fact that he’s eccentric. But being eccentric, he says, is not the same as being defective. “We don’t say someone *has* eccentricity,” he tells me. “We simply say he’s eccentric. It’s not a disease.” He vigorously resists the idea that he needs to be fixed because, as he would say, on *his* planet he ain’t broken.

Despite sharing a given name with the autistic savant portrayed in the movie *Rain Man*, which brought autism into the popular consciousness, Ray has no single massive talent set against a backdrop of disability. And he doesn’t look or act much like the autistic characters that are played—one might say “parodied”—on popular shows today. Those characters usually live in nice apartments, surrounded by well-dressed, indulgent, neurotypical friends. They possess prodigious intellects, and their awkwardness is played for laughs. A favourite plot device is to put the science geek in a room with an attractive neurotypical woman in a low-cut top and watch the fun. It’s always just enough to make autists somehow endearing despite their rough edges. Sure, Ray can talk intelligently on many topics, but he’s no genius, and he cannot entertain and amaze the crowds with any particular super-ability. Lacking any such schtick to hide behind, he writes, with a note of melancholy:

It is bitterest gall to me that I’m not some sort of savant. It would at least compensate for all the rest.

Although he grudgingly admits at this late date that he meets certain criteria that *might perhaps possibly* earn him a place on the autism

spectrum, he's wary of being formally diagnosed with anything, and thus far, like many of his generation, he hasn't been. "Why," he asks me, "do we need a *syndrome* to describe people who say what they mean?"

The fact that he remains undiagnosed is not for a lack of trying on my part. But no sooner had I discovered that there was a plausible explanation for his puzzling combination of intellectual gifts and social deficits, and that it is called Asperger's syndrome, than the shrinks went and rewrote their book (the *Diagnostic and Statistical Manual of Mental Disorders*, or DSM), eliminating it as a diagnosis. The correct term as of May 2013 is "autism spectrum disorder." I was still trying to sell Ray on the fact that he was an "Aspergian" when he heard the news and called me up. "Hey," he said gleefully, "I hear I'm being delisted!"

Brainy nerds like Ray no longer have their own clubhouse; they're now part of a vast continuum ranging from the highly gifted but "mostly always terrified" to the severely incapacitated, from the loquacious to the nonverbal, the highly focused to the fixated.

Ray is not happy about the change. Over time he has become more or less reconciled to having Asperger's syndrome even though, as he has made abundantly clear, he's never going to be entirely comfortable sporting this or any other label. But if forced to pick a name for his "disorder"—sorry, Ray, that's what they call it—he'd rather not "have" autism spectrum disorder. He feels no kinship with deeply autistic people: they seem determined *not* to communicate with others, when he was born to do precisely that.

Here, for the record, are his feelings on the matter, delivered with smashing political incorrectness:

I shouldn't say this, but I hate being referred to as "autistic." Asperger's I can handle. Even if you want to advocate for "the spectrum," it seems wrong to use "autistic." It just paints the wrong image in the mind; I think Asperger's is more descriptively accurate. I know I probably shouldn't worry about it.

Actually, he probably should. There is no longer any such diagnosis. Even if there was, would he be comfortable wearing the name of such a controversial figure? Dr. Hans Asperger, the pediatrician for

whom the syndrome is named, was until recently hailed as patron saint and saviour of the unique subset of autistic people who bore his name. He has often been quoted as saying, “For success in science or art, a dash of autism is essential. [It imparts] an ability to turn away from the everyday world, from the simply practical, and to rethink a subject with originality so as to create in new untrodden ways.” A “dash of autism”—I’ve always loved that. But Asperger has been posthumously accused of cherry-picking “high functioning” autistics to study while tacitly surrendering the more “defective” children to the mercies of the Nazi eugenics program. Autistic people are renouncing his name in droves.

But Ray is not quick to jump aboard the bandwagon demonizing Asperger (or any other bandwagon, for that matter). In this email, he goes on a proper rant about historical revisionism:

It is the fashion these days to try to remove everyone from history who has been accused of some violation of our current politically correct norms. The Americans will tear down the Washington Monument one day because Washington was a slave owner. Martin Luther King was known to attend orgies, JFK was a womanizer, Tchaikovsky was a pedophile, Jefferson had a black mistress. Werner von Braun was a Nazi, but he put a man on the moon.

Many people who did bad things would not have done them had the situation been different. Hans A. did not ask to be born when and where he was born. Even if he did some bad stuff, we will never know if he enjoyed it and we will never know what we would have done in the same situation and I think we should give him some charity. We still call it the Gregorian calendar even if we have since discovered that Pope Gregory was not a very nice man. Can we only name things after nice people? If we discover that Amerigo Vespucci beat his wife, will we be renaming North, South and Central America?

It's Asperger's syndrome, damn it.

And for the record I don't want to be labelled autistic. I don't sit in a corner all day banging my head on the floor. The "spectrum" is not something I want to be on.

Ray can take that up with the proper authorities. Until the dust settles, I will use the terms "Autism Spectrum Disorder" (ASD) and "Asperger syndrome" (AS) interchangeably, as the latter term is still in common use, despite Dr. Asperger's latter-day fall from grace.

The DSM-5 is a behemoth compared to its earlier incarnations. It contains many new diagnoses, including Social Communication Disorder, with symptoms and behaviours that overlap those seen in Autism Spectrum Disorder. Ray's a shoo-in for that one. He'd happily admit to having a galloping case of Social Anxiety Disorder, too (around since the DSM-4), and maybe we could throw in Avoidant Personality Disorder from the DSM-3 for good measure.

Ray likes to point out that "social anxiety" used to be called shyness, which is not a disease—or it wasn't until the shrinks invented "social anxiety disorder" and started medicating it. "Oh no!" he says, eyes wide and fingers fanned out beside his face in mock horror, "Call an ambulance! My child has *shyness*!"

To further illustrate the absurdity of our rush to medicalize normal human behaviour, he indicates our brother-in-law, Mike, who has invited a bunch of us over for dinner and is busy cooking it while we lounge about in his living room with our pre-dinner drinks. "Does Mike have 'jerk syndrome'?" asks Ray theatrically, waving his beer in Mike's direction. "No! We simply say, 'Mike is a jerk.'"

My brother is deeply ambivalent about the whole autism/Asperger's thing. On the one hand, he acknowledges that an official diagnosis could be a lifesaver in sticky situations; on the other hand, he doesn't want his experiences and his way of thinking arbitrarily boxed up and labelled so that everyone can presume, based on a five-minute Google search, to know precisely who and what he is. Can you blame him?

But Ray has also made it clear that he would not elect to be a garden-variety neurotypical like me for any money. He told me not long

ago, “I don’t have the slightest desire to be normal. I may be a freak, but I don’t want anyone to change me.”

The truth is, I cannot imagine any other version of my brother than the one I have. But when I tell him I don’t need him to be “normal”—whatever that is—he isn’t buying it.

“I believe you believe yourself,” he scoffs. “But the entire world is a conformity hammer. As a round peg, you slide through the round hole with barely a tap of the hammer. The square peg in the round hole has an entirely different view of things.”

Ray wears his sharp corners with pride, even though it means he will continue to feel the bash of the mallet all his life. He bears his loneliness with proud stoicism—that is, until someone like me comes along with a sanding block and a sheet of 60-grit sandpaper and offers to lovingly smooth off those edges. Then just watch his hackles go up.

People sometimes ask me if I can tell when Ray is just being difficult and when his behaviour can be excused by his—ahem—“condition.” How I wish I knew the answer! I think his intentions are almost always good, but he’s just a man, after all, and a wounded one at that, so any answer I might give would be a complicated one.

He is always thinking up novel ways to do things. “Standard procedure” is nothing more than a challenge to his ingenuity, a gauntlet thrown down.

There are times—though I bet he’d deny this—when he does things just to be contrary. He enjoys his status as a nonconformist and looks for ways to distinguish himself from the herd. Oh sure, he does that without even trying, but he’s after the bonus points. If “we” do it *this way*, Ray will do it *that way*.

Even his cellphone’s voice mail message shows his contrary streak:

Ray Andrews here. Please wait a few minutes for me to call you back before you leave a message. Voice mail is by far the worst possible way of getting a hold of me. *Beeeeep*.

I grow incrementally more exasperated each time I hear that message telling me not to leave a message. “Just text me!” Ray says when I

suggest with some impatience that he check his voice mail like a normal person. “Text me! Way better!” Not way better for *me*, though, especially back in the early days of cellphones when I had an old flip-top model like his, requiring several ulcer-inducing minutes of pecking and poking to get a simple message out.

A family friend named Steven was making the trip by ferry from Vancouver to our home here in Gibsons on British Columbia’s Sunshine Coast. Steven is a humble and diffident man for whom Goog-balong is an exercise in agony. I was making a nice dinner for him and tried calling to invite Ray. I listened to that infernal message several times, but he didn’t call back as advertised. I finally resorted to leaving a voice mail—“by far the worst possible way” of getting a hold of him. I later followed up by getting in my car and driving to his place—honestly, it was faster than texting—to invite him in person. “Oh, sure, love to,” he said. “Just text me when you know what ferry Steve’s on.” So I did. I texted him three times, starting mid-afternoon. The last time was during dinner: *Ray, Steve is here—where r u?*

Ray was a no-show. I tried to brush it off, but the next morning I woke up feeling uneasy. He is usually reliable and punctual. What could have happened that would cause him to pass up good company and a roast beef dinner with all the trimmings? My phone call to him again went unanswered: “Ray Andrews here. Please wait a few minutes for me to ...” I snapped my phone shut. One of my sisters said she was going out and would check on him. A short while later, I received a text message from her that said, *All well. Ray says you didn’t email him.*

Speaking of email, he even refuses to do that like everyone else does. Instead of writing replies above my messages where his cursor is obligingly blinking at him, he’ll scroll down and stick his reply below mine. Worse yet, when he and I are having an involved email discussion and it’s his turn, he “tidies up” our correspondence by copying and pasting dismembered bits of text into a fresh new email, wedging his comments between those sentence fragments instead of letting the conversational thread unspool in a nice long stream.

When I complain or entreat him to humour me by doing it my way, just this once, just for me, pretty please, he offers to come over and install his obscure email program on my computer so that all replies

will automatically indent with an ever-increasing number of chevrons the way his do. One must count chevrons to figure out how many times a given line of text has shuttled back and forth.

I once spent a whole evening copying and pasting swaths of text from dozens of emails, patiently reconstructing the flow of our conversation. I used colour-coding and italics to show who was “speaking.” Satisfied that it all made sense at last, I sent the reworked version to Ray. He did not appreciate my efforts. He asked me to cease and desist:

Babs, would you please correspond using the “indent” style? As I see this, it is a mishmash of different fonts and colours that is very difficult to read. It might be an Aspie thing, but I find the overuse of fonts, colours, sizes, italics, etc. to be not only unhelpful but positively disturbing.

His singular style extends into every corner of his life. He has an assortment of cheap drugstore reading glasses, the kind that come with peel-off stickers on the lenses stating the strength of the magnification. He uses different powers for different tasks, and he likes the stickers right where they are, thank you very much—it’s easier than squinting at the teensy numbers inside the arms. Almost every single person, upon first noticing one of these stickers, will helpfully try to peel it off, assuming he’s just forgotten to do so himself. It startles Ray to have people—sometimes perfect strangers—reaching for his face. I’ve seen him jerk his head away, hands flying up to protect himself from their darting fingers, but he’s sticking with the stickers.

Almost everything Ray owns he has either built himself or modified in some way. A few years ago he started teaching himself to play the cello. One evening my phone rang. The call display indicated that it was him, but he didn’t respond to my hellos. Just as I was about to hang up, I heard a scraping sound, followed by an unearthly series of quavering squawks. It took me a minute to realize that I was being treated to a screechy rendition of “The Swan” from Saint-Saëns’s *Carnival of the Animals*. I found myself blinking back tears, touched that he had chosen to favour me with his amateur performance—but also because it was so sweetly, ear-splittingly awful.

Ray has done some after-market modifications to his cello to make it work more efficiently:

I replaced the Stone Age wooden tuning pegs with modern mechanical string winders, like on a guitar. This makes tuning much easier and narrows the head, which makes it possible to rest it on my shoulder.

What that means is that the cello now has ugly chrome bolts sticking Frankenstein-like out of its neck.

Ray goes on to explain his rationale for butchering the beautiful instrument:

It is now braced much more solidly, and it becomes possible to play “thumb over” across the whole length of the fingerboard. Also, the lower and more sloped holding position means that the forearm is more perpendicular to the fingerboard, which strikes me as much more natural. Besides, that way it’s possible to see the fingerboard while playing, which of course invited me to draw frets on it so that I know where my fingers should go. This would no doubt make any normal cellist retch. Oh, and I’m on the verge of drilling a few discreet holes in it to control resonance. Now if I could just learn to play the damn thing ...

“And didn’t you cut its pretty head off, too?”

Alas, the scroll interfered with the winders; there was no avoiding it.

“Well, I think you’ll burn for that.”

Ray is fatalistic:

I’ll burn for so many things before that even comes up on my charge sheet that it will hardly make a difference.

Regardless of what Ray “has” or doesn’t “have,” the fact is that placing computers between him and me causes his social deficits to magically disappear. That I don’t have to deal with his atrocious handwriting and that there is a spell-checker to catch and correct most of his spelling mistakes—these are mere fringe benefits.

When Ray composes his thoughts on a keyboard, he hits the pause button on the Goongbalong action. The players are mercifully frozen in place while he calmly plans his next move. He can rewind the tape and play it again in slo-mo. He doesn’t make the verbal gaffes that have caused him—and those around him—so much pain. Over the years of our email correspondence, I have come to think of these two aspects of Ray, the speaking version and the emailing version, as almost separate individuals, and I have given them capitals: *Writing Man* and *Speaking Man*. Ray’s gone along with it, although he sometimes refers to Writing Man as Thinking Man, Inner Man or Silent Man—so we use those terms interchangeably. After five decades of misunderstandings, we have finally found a sturdy bridge between ourselves—the written word.

Writing Man, unlike his jittery spokesman, will tackle any issue, answer any question willingly and with astonishing fluency. His thoughts are honed and perfectly polished before they are sent out. When my brother places his fingers on the keyboard, the inner, voiceless man shimmers into view. Respond by email and you will find yourself in conversation with Writing Man. The real Ray.



If Ray can turn his dentist’s receptionist into a homicidal maniac during a routine visit, you’d think he would be terrified of strangers, but that is not the case.

Fact is, I can chat with a stranger in a lineup as well as the next guy. I even tend to be a bit of a joker.

Yes, Ray can perform this common ritual like a pro—I’ve seen him do it. His proficiency in talking to strangers may seem surprising given his sometimes paralyzing social anxiety but think about it: there is always a “topic” during these brief exchanges; no mind-reading is

required, and there is little, if any, emotional reciprocity expected. And though Ray can't avoid seeing his dentist's receptionist at least once or twice a year, he will probably never see the stranger in the lineup again, so there's nothing to lose.

It's a different story when he walks into a social gathering where he must interact with people he knows superficially. Every one of these people—who are neither trusted friends nor strangers—represents a clear and present danger to Ray. In fact, they are the most intimidating demographic on the planet. He explains:

The trouble is with folks I *half* know. With a stranger, nothing much is expected beyond simple politeness, and with family, well, they know what to expect. But with the Halfers, the rituals of Goongbalong are at their most intense. You go through a sort of act of pretending to be very close friends when you aren't.

The minute Ray comes eyeball to eyeball with a Halfer, a macabre dance begins. An elaborate series of Goongbalong manoeuvres must be performed—and performed *correctly*. If the Halfer is a loud, chattering woman wearing a big smile that shows most of her teeth, it is safe to assume that Ray will be petrified. If, in addition to having her volume set at maximum, she is showing a lot of cleavage, wearing garish makeup or displaying any other prominent features that attract Speaking Man's attention, he's doomed, and he knows it. With no topic of mutual interest queued up and the Halfer bearing down on his position, his brain sends the distress signal: "*Warning! Chit-Chat Ahead!*" He fights a rising dread as he scans for the nearest exit.

"You have no idea how unpleasant it is for me," he says of navigating a room full of casual acquaintances. "Nobody does." Halfers always appear warm and friendly—this is a primary doctrine of Goongbalong—but he knows they are furtively totting up his infractions on their scorecards without ever breaking their smiles. He hugs the wall and prays no one will approach him. When that fails—and it always does—he makes a desperate gambit to steer the conversation somewhere safe and solid, away from the dangerous, swirling eddies of "Nice-to-see-you-again-you're-looking-well-how've-you-been?" and the unwritten

but mandatory responses to those vacuous inquiries that so utterly elude him and upon which his acceptability as a human being is graded. The clock is ticking, it's his move, and Speaking Man, in his terror, blurts out something he fervently hopes is appropriate. Thinking Man assumes the crash position and covers his ears.

Honesty, Ray adds, doesn't pay in a neurotypical world:

When I try to make small talk with a Halfer, I will intend to say something like, "You are looking very well today," but I end up making some honest observation about how the person looks—and that is always a mistake.

It was a long time before the awful truth finally sank in:

I find it very easy to talk about pretty much any subject, but almost impossible to talk about nothing. "Normal" people find talking about nothing to be very important. Sometimes I just tune it out. Seagulls express their "matedness" by squawking and babbling. People do that too. I don't mind it. I just can't do it. I was probably in my thirties before I realized that when someone comes up to me and says, "How are you?" they are not actually asking a question. You say, "I'm fine, how are you?" But you're not asking a real question either ...

Ray is never going to be able to approach a knot of neurotypicals and ooze right in with easy grace and charm. He knows his only chance of getting through the ordeal unscathed involves playing a socially acceptable version of himself, but he has a tough time with the necessary charades. It is undignified, he says, to be required to ape the behaviour of neurotypicals to gain their acceptance. Besides, it makes for a thin disguise, one that can slip at any moment, revealing him as an impostor. But in he goes, talking about nothing as though his life depended on it. Because in a way it does.

This is Goongbalong, and oh, how he resents having to play the despicable game. On his planet, it's a capital offence.