

# No One Afraid

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**SHANE NEILSON**

**E**VERY WEEKDAY, I WALK MY SON KAZ TO ELEMENTARY SCHOOL, A NONDESCRIPT brick single-floor structure. Small parking lot, unmanageable snarls of drop offs, huge library (but few books), an athletic field that will never get the landscaping love it needs. He doesn't approach any other children, though I encourage him to do so. No other children approach him. Later, when I pick him up from his aftercare, I arrive looking to see if he is engaged with other kids, but each evening he is either crafting with an adult, or he sits alone. On occasion, I've walked past the school playground, looking to see what he's up to during recess. He sits on a bench, by himself, and returns inside when the bell rings. When I ask him why I never see him play with anyone at school, he says, *Because I'm solo, daddy.* After a pause, he repeats: *I'm solo.* Irritated at being asked once more as he nears the end of his time in elementary school, he responds to my habitual question with, *Why do you want me to have friends, daddy?* I think: because I want you to have what I didn't have. I say instead: *Because friends are more fun.* Kaz responds: *But I'm solo, daddy.*



At every single meeting with a public-sourced disability professional—behavioural consultant, social worker, occupational trainer—I endure the first five minutes of our meetings as the typical dad, meaning that the women all look to my wife as the primary source of information. Once the five-minute mark hits, I explain that I am the primary caregiver, that I have what they term the 'instructional control relationship' with Kaz. Or, as he and I term it: 'we're friends.'



Buster Perley, the intellectually disabled man who lived with my grandparents, loves to sit in a folding chair near the Trans-Canada Highway, spending entire days bronzing in the sun, watching cars and tractor trailers move up and down. The few times I visit my grandparents as a young child, Buster extends his hands towards me and mock-undulates his fingers, saying, *I'm going to get you*. I, of course, love Monster Game, and scream while running away. Whenever he sees me, he sticks his hands out again and waves his fingers. Then I disappear. One day, I witness Buster complete his one job at the farmhouse: dishes. His slow body, bending over, standing straight, bending over. My grandparents are paid the lion's portion of his disability pension for his care.



I first learn of the existence of the American poet David Ignatow via William Carlos Williams. Devouring everything I can about Williams—his poems, first of all, no small task in terms of bulk, but then moving from there to the autobiography, the biographies, the short fiction, several tomes of letters (god, Williams really let it rip in correspondence), and ending with his criticism—I somehow come across Ignatow, whom Williams once praised in a review in *The New York Times* in 1948, a review that became essentialized in the form of a blurb that came in for a lot of heavy lifting throughout Ignatow's career. The good old pediatrician appreciated Ignatow's writing for self-serving reasons: Ignatow is clearly a (bad) working-class Williams clone. (I celebrate the class element, while insisting on the aesthetic verdict.) My enduring interest has nothing to do with Ignatow's poetry, which I disdain and would warn anyone away from. Instead, the story of his fraught fatherhood continues to obsess me. I think of Ignatow and his disabled son at least once a week.



In the Janeway Hospital emergency department, a young male physician looks over a new crop of family medicine residents, myself among them. Self-important, invested with grandiose purpose, he wishes to impress us. Short blonde hair, stylish neon red glasses, expensive leather shoes—it's as if he's trying to score while he works. At any rate, Mr. Creep-the-Students stares us down during his initial introduction and says, *If you work here, you need to know something. When it comes to the illness of a child, something happens to parents. They become fighters. You need to know that even if you're dealing with the most easygoing of people, when it comes to their children they will refuse that which they would otherwise accept.*



I am seven years old. My mother teaches me how to fill the dishwasher. She has a system: plates in a phalanx; bowls according to how not to bend the tines. Precise placement of utensils. After every meal, it is my responsibility to clean off the table and deposit dirty plates and cutlery into the dishwasher. I am expected to do this every day, every meal. Back and forth, bending over. Straightening.



How am I supposed to show my son how to make friends, how to be a friend, if I myself do not know how?



Since the 1950s, the lion's share of research into the parenting of intellectually disabled children has been conducted with mothers. This has only started to

change in the past ten years. Initially, the theory guiding research was Freudian: parents typed according to the grief model in *Mourning and Melancholia*. This simplistic view has become vastly more complex over the years, moving to the equational 'Double ABCX model' that explains parental stress. In the model,

X = the stress of having a disabled child

A = the specific characteristics of the disabled child

B = a family's resources, internal and external

and C = the family's perceptions of the child.

The 'Double' part of the equation means simply that the equation can be run again later as variables change. An open system. Grief evolves, adds, sediments. We have long known that the mothers of intellectually disabled children have poorer psychological health as a cohort than mothers of normative children. Only lately has the finding been confirmed in fathers. Assignment of variables in our case:

Double = pre-existing mental health diagnosis + grief of diagnosis

A = Kaz's behaviour, things no one else will know unless they are here, unless they see, unless they are family; things anyone who overhears will discount, or use to blame me.

B = considerable internal resources but zero external resources

C = love and fear.



When I am eight years old, my father teaches me how to take out the garbage. We use empty old oil barrels, bottoms almost rusted through; the trick is to get the dolly underneath and pull back in a fluid motion so that the barrel won't overturn. Each week, two barrels, Thursday mornings, several terrifying months of screamed instruction before I learn the trick to his satisfaction.



The first appearance of Ignatow's son (also named David, let's call him DJr) occurs quite some time into *The Notebooks of David Ignatow*. The reason is perfect: DJr, when in the middle of a psychotic break as a young man, had been loading his father's handwritten journals into a wheelbarrow and dumping them into the Hudson until his father caught him in the act. Journals from 1935-1939 and 1941-1949 all go into the drink. Because DJr was born in 1937, one could think of this action as representative of frustration or anger he bore towards his neglectful father, and there is some basis for this interpretation as corroborated by DSr. But a literary mind who reads the *Notebooks* might come to a different conclusion. Entries from the early years contain dim philosophizing about the literary life, dross that obscures the compelling material that is to come: the story of the Davids. Thus son David was acting in his father's best interests in a sense, functioning as a ruthless editor, protecting his father from himself.



I am ten years old. My father teaches me how to start a fire. It is now also my responsibility to light the wood stove before my father returns home from work in the evening. He shows me how to place paper, what

kindling to use and how much, how to place sticks, how to distinguish between hardwood and softwood. Don't overuse paper and kindling. I need to be shown over and over and over again. Over and over and over. Screaming, over and over.



*Kaz, I say. That's not friends.* Kaz is harassing his sister, trying to make her cry, claiming that Biggers, our cat, loves him more than her. *Kaz, I say. That's not friends.* Kaz rolls his eyes, stomps his feet, and rocks his chair in protest for not getting a treat. *Kaz, I say. That's not friends.* Kaz refuses to participate in routines, preferring to sing a song about how he will never, ever do anything but play video games and eat choccos. Sometimes I repeat the rationale: *Kaz, friends are cool and they help each other and they like each other and they get along. I want to be friends. Do you want to be friends?*



Statistics concerning the divorce rates of parents of intellectually disabled children are depressing. Though numbers vary, a conservative choice is 80%. This figure is absolutely borne out in my personal travels. My son's intellectually disabled classmates are almost all children of divorce. At the dad-of-disableds group I attend, divorce is frequent, but the cohort is heavily skewed to fathers of young children—they still have time to meet their fate. The reason rates are so high is simple: intellectually disabled children, when compared with neurotypicals, have increased rates of behaviour problems, less emotional expressiveness, do not respond to cues in their environment, and have communication issues. Everything is harder, and marriage is hard enough. I stay married because I made a pact with myself at ten years old, standing in the

frozen dew after the latest rage of my autistic father. I resolved to fall in love and have a family, for my children to be loved, for things to be different. The little boy didn't think it that way, exactly, for his resolution was more of a feeling, but it has proven a passion that has burnt high his whole life, occasionally roaring higher, should the occasion require it.



When I am fourteen years old, I begin to notice that nothing is expected of my brother. He has no chores, no responsibilities. He does not have to clear the table, take out garbage, or start a fire. When I protest, my mother offers no response. *You just have to get it done*, she says when I bring it up. She should have added, "Disablerella."



I take Kaz to what we call 'Friends School,' a Y-based program partnered with the cities of Cambridge and Guelph. There, Kaz makes a small snack, plays a game, and has unstructured time interacting with other intellectually disabled children. When I enter the space to drop him off, we must be careful not to let the serial eloper burst past—a child who flees when the door opens. When I'm inside, another child might immediately try to make friends with me, asking me who my favourite hockey player is, if I know his stats, and if I don't, then how about this player with these stats, or if I know what one huge number divided by a slightly smaller number is, and if I don't, then the answer is. . . Kaz is welcomed heartily by a smiley young youth worker and bid to come sit nearby, where other children sit, unmoving. I leave with that version of Kaz in my mind: welcomed, walking towards motionless kids.



There has always been something between my son and me. Actually, someone. Since Kaz developed a personality at around the age of six months, the energy seemed familiar. Reactive; resistant; defiant; angry; oppositional; violent; insistent; harassing—as if my father’s spirit skipped a generation and lodged in my son, so many similarities in temperament and action. But then, who can say that my son is not himself? That I am not re-enacting trauma, distorting our relationship, forcing it through a filter? How can one be a father to a child if one is somehow parenting the child as if it were a violent, neglectful parent? Why be unfair to both of us?



According to my father, I cannot do something fast enough, well enough, or at all. I cannot anticipate what he wants. I freeze, making things worse. My brother can easily do what my father requires, meaning that he validates Doug’s judgement of my worthlessness. In parallel, my son cannot do what I need him to do. He cannot follow more than a single instruction, and often not even that. He cannot intuit what to do, and if a task requires more than a few steps, he has learned not to try. When he was small, I had a choice. I could terrorize him, break him, make him fear me. I could hurt him. I could do what my father did. Take my turn. But there was never more than just echo, a palsied memory that underlay these encounters with my son. Unlike my father, I dislike acting out anger. I am reluctant to hurt someone else physically, or to be verbally aggressive. It is as if my body brushes off the inclination, the possibility. The only circumstance which provokes this energy in me, in which case I welcome it, stoke it, is when my children are threatened, mocked, or excluded. Then passion rises and seeks release as fury.



We sit at a long table in Sunningdale Public School: a principal, a secretary, the teacher, my wife Janet. Me. Thin, gray, and mousy, Teacher’s embittered, but her anger isn’t with Kaz or us. Before the meeting starts, in an aside with my wife, Teach says, *I’ve asked for help with him. An EA. Something. I’ve asked several times.* Teach is near retirement. Older, anyway, must have just a few more years to go. A cliché runs through my mind: grade one teachers love to work with children. The cliché does not seem true in this case. *Do you think he knows?* she adds. *Knows what?* my wife responds. *Knows that he’s different,* she says. A few minutes later, everyone has notebooks out except for us. I reach into my bag, take out a torn strip of paper, and pretend to write things down. Though ridiculous, this gets a reaction. When I start to write, everyone else’s note-taking redoubles even though the meeting hasn’t officially started yet. The principal, an obese man with a small moustache and heavy, raised moles on his cheeks, says *We’re here to help get Kaz learning where he belongs.* Me: *He doesn’t belong here?* Principal: *Oh, I don’t mean it like that. I mean, he should be with other people at his level. Otherwise, he’ll feel left behind.* Kaz’s teacher says nothing. This is, of course, what she wants—to be rid of him. So I respond directly to her, realizing she was playing both sides all along, *You don’t want him in your class?* She opens her mouth, but the principal cuts her off. *It’s not like that,* he says. *We want Kaz to be where he can thrive.* Translation: we want Kaz to go somewhere else, to not be here. We can’t accommodate him. We won’t. Fine. I don’t want him here either. But I’m going to cause trouble. Me: *You know she told us she asked you for help with Kaz repeatedly but never got it. A month ago she said the only thing the EAs do in this place is wipe kids’ asses.* The notetaking stops for a moment, soon redoubling furiously. Only the principal doesn’t return to taking notes.

Red-faced, Pickwickian, sweating in a kind of anger, he says, “None of this is helpful. We’re trying to help Kaz.” Anger and help. Anger and help. I already knew this was never about help, and now I’m more certain.



Since the age of twelve, Kaz has learned in a self-contained classroom, meaning he’s educated with other children who have intellectual disability. A few months into his first year of high school at age fourteen, I receive a call from his teacher. *Kaz is being taken off work placements, she says. He’s just behaving too silly. He’s too immature for this right now.* The placements involve stocking shelves at a Treasure Hunt and making sandwiches for a soup kitchen in the basement of a Cambridge church. Placements are the apotheosis of his time at Galt Collegiate—the goal is to produce a human who can devote themselves to mechanical tasks for a few hours of the day. Half of the pedagogy is knowing how to take the bus to get to the work site, the other half is doing the actual work. *What’s he doing?* I say into the receiver. *It’s not bad behaviour, really, she says. He just doesn’t seem to want to do the work, and so he wanders around being annoying instead. The TAs need to focus on everyone, not just him.* I know what she means. Her tone isn’t angry, but fatigued instead. *Kaz will still do work in the classroom, different assignments that will be easier for him because he will remain in this environment, without transitions.* This is the difference between not-help and help, between anger and help vs. sad help. Rather than get rid of him, they work with him.



DJr appears in *The Notebooks* as a screaming need, a jolting pain, trial and tribulation. After what I suspect is a prodromal period during his teenage years—pro-

gressive social isolation, general disorganization—DJr begins to hear things, see things, believe things. DJr has religious delusions—like me, he can see Jesus. Descriptions in *The Notebooks* are glancing, too thinly episodic, mere shards of clustered anecdotal details; Ignatow still seems like he has a lot to learn about true care and dedication, of dailiness. That said, Ignatow properly agonizes over how he should have paid more attention, how his intensity of affect and resentful attitude towards intrusions upon his writing time partly sponsored his son’s schizophrenia. In contrast with scant accounts of care, Ignatow obsessively confesses his guilt. Good confessions connect with the truth, but these feel unseemly, as if guilt is the point, rather than action. The guilt has to be enough for him and for the reader to believe that Ignatow realized he was responsible for his son, finally, in some significant way, that he realized he must respond to the call of his son’s psychosis, medication noncompliance, rantings, property destruction, hospital admission, hospital readmission, and, finally, long-term residential treatment at an asylum. We never hear from son David himself, but such is the case with most disabled people. The guilt is not enough for me, as a reader, to believe. For to be a father of an intellectually disabled child in this world is, in the early days, to be an angry helper. Not like Principal or Teacher, but like Father.



A’s shaking mad, jumping mad, fist up mad, crying mad. His desk’s rocking. Stamping mad. Screaming mad. Who knows why, and does it matter? A’s angry, he’s going off! He needs soothing. In the self-contained classroom, the children do as their teacher, Mrs. Barber, has taught them. In the Barber Shop, students support other students. They try to understand and listen to others. But A is past this point, he’s furious. So

the kids do what has been done for them in the weeks and months before. The kids sing their songs to A, to get him to laugh.

*Don't worry, be happy*  
*Don't worry, be happy*

A settles somewhat. He's still shaking, but spilling fewer tears. The kids bear down with smiles into the next song. They love singing during class—better than math and printing. New song:

*Every little thing, it's gonna be alright*  
*Every little thing, it's gonna be alright.*

A starts to sing with them, and the kids know that, once again, love has won. He starts to sing too, and when the song is over, A says he lost his purple pencil. Later, B finds it on the cot where any tired child can go and lie down and nap, if they want to. And A wants to, again.



Picking up my son at a horse-riding camp open to intellectually disabled people just outside of Guelph, I overhear an undergraduate-age woman talking to another young woman. They both wear blue T-shirts that mark them as counsellors. The tall one: *It takes privilege to treat people badly, I guess.* The small one: *Yeah, the ID kids all seem to get along great. They play with one another. It's the normal kids that are the little shits. They can be so mean.*



At the parent-teacher interview for Kaz, his high school teacher says, *We like Kaz. He could talk a little more in class, but it's just his first year. I do think he could*

*be more social, though. For sure. He spends most of his time alone, even during lunch hour.*



Since Kaz was diagnosed with intellectual disability, I notice adults with ID in the community when I wouldn't otherwise, subtle cases like ones taken to Tim Hortons to have a sugary drink by their care worker, or ones brought to the Toronto Zoo. The case-workers usually gaze at their phone most of the time. Sometimes they seem angry, the disabled person somewhat spooked. The feeling is completely different when I see disabled adults cared for by family: though the parents are older, everyone seems engaged and unhurried. What will happen to my son after I die? Who will take him to Canada's Wonderland, help him negotiate space in a crowd? Will he be relegated to a changing guard of uninvested, paid care workers, transients who could never be expected to actually care about him as I do? Workers who think of him as a case, someone who can be abandoned for an easier, more lucrative gig? Where will my son live? Who will ensure it is safe? Who will fight for him? Who will love him?



With the help of a disability worker we've hired privately from outside of the public system, we devise a schedule for Kaz to follow when he returns home from school. First, a snack at the table that he helps prepare. Second, cleaning the table. He must return all the dishes, condiments, and implements to the kitchen, then wipe the surface with a wet cloth. Third, he must sweep the dining room and living room. Fourth, he must clean himself in the shower. All of these tasks require careful assistance. He can get distracted by anything, so each task is subdivided into smaller tasks.

Each piece is systematic—start here, move this way, end here. Showering is the trickiest—he is shown how to massage his scalp with his fingers, and to do so we need to use the hand-over-hand method. Move fingers, move fingers, move hand back, move fingers, move fingers. A typical child might implicitly know how to do some of these things; almost every child would be able to duplicate a task after being shown once or twice. Kaz requires diligence and patience, standing beside, sharing the activity in a slow-together way. What would take me ten minutes to do takes him two hours. Redirect. Start again. Redirect. Hand over hand. Start again.



This time, it's P. No one knows why. No one said anything. P just got mad. He flicked his tongue against his upper lip, punctuating a screaming sound, tears flowing around his open mouth. But Mrs. Barber knows the answer is not figuring this out, not discovering what's the matter. What's important is soothing P, and to do that, the class must coordinate its care, sing a song. *Happpppppeeeeeeeeeeeeeee*, she sings, but it's too soon for the class to pick up. *Happpppppeeeeeeeeeeeeeee*, she continues. Of all the Change Mood songs, this one is the class's favourite. A few join in. *Happpppppeeeeeeeeeeeeeee*, *Happpppppeeeeeeeeeeeeeee*, new student recruits coming after each declaration of joy. Once this motor's turned over, Mrs. Barber interjects *Clap along if you feel like that's what you want to do*. The whole class is in on this now, everybody digging the tune, loving the opportunity to participate in happiness, the happiness level in the room increasing with each chant, happiness made manifest, brought into being. The students with desks around P clap, because clapping is what they want to do. After about a minute, P starts to sputter, then sing the words that, after just three repetitions, stop the tears.



What I love about *The Notebooks* is the sense of a selfish man forced into a reckoning about life and poetry. After scores of insipid, self-involved pages simulating insight about the intersection of art and life, the asteroid suddenly hits Ignatow's solipsism, making him realize that there comes too great a cost to leading such an existence. I love also that his transformation is a failed one, at least from where I stand. Ignatow makes it halfway, which is welcome, an achievement, but still a failure to this outsider left wondering if meeting children halfway is ever enough. DSr no longer writes out his ego, thinking only of himself; now a reader can encounter passages like, *I have had a feeling of catastrophe in his life ever since his first hospitalization. He is removed from life and yet has to live a life of his own, divorced from the general life. It is a life of exile and punishment*. Such prose proves Ignatow has changed, he can now partly see his son and realize what has been lost in an empathic way, though solipsism remains (the passage continues, *What has he done to deserve, rather what have I done to deserve his exile?*). Appreciating DJr for who and what he is—that remains impossible. DJr is mostly grief, guilt, and loss for father David. So it was with me too, until I noticed how much Kaz's catastrophe wrought changes in my life that had long been necessary; that my Before-Work needed abandoning and New-Work needed to start, a slow-together work that renovated my relationships with my wife, my eldest daughter, my colleagues—everyone. Worry will never disappear; grief for what might have been for my son may never disappear; but the negative emotion is alloyed with gratitude for being forced to make beneficial changes I would never have contemplated. Just as son David dumped his father's notebooks into the Hudson, Kaz's disability finally convinced me to let go of my desperate wish to simulate normative life. And, most of all: Kaz taught me about fatherhood.

SHANE NEILSON



Any child out there hurting would want a little platoon of kids singing to them, taking genuine pleasure in the song. With no one afraid of them, no one afraid of difference.



Kaz has a friend now in his class. They meet at the local

library and talk endlessly about Hot Wheels. How you can get them on ebay. Old Caddies. Dodge Chargers. They play Switch. Kaz rides a scooter to the library and locks it in a religiously careful way so it won't get stolen. Downtown Cambridge is not exactly safe, though safer than the route to McDonalds. He spends hours there, unsupervised, with another human being that is not his immediate family, not someone paid to take care of him. Someone who wants to be friends. And with this single friend, he smashes my personal record.