

# Life as Jamie Knows It

by MICHAEL BÉRUBÉ, PhD

In his 1994 book, *Rethinking Life and Death*, Peter Singer famously claimed that “to have a child with Down syndrome is to have a very different experience from having a normal child. It can still be a warm and loving experience, but we must have lowered expectations of our child's ability. We cannot expect a child with Down syndrome to play the guitar, to develop an appreciation of science fiction, to learn a foreign language, to chat with us about the latest Woody Allen movie, or to be a respectable athlete, basketballer or tennis player” (213). For those of us who work with people with Down syndrome, in whatever capacity, this is a deservedly infamous passage; and much of what I say tonight will consist of an extended rebuttal of it. Not that I have to do much work on that front; for the most part, my rebuttal will consist of accounts of Jamie's life and his progress over the past ten or twelve years. But I want to admit at the outset that back in 1994, when Jamie was only three, I might have fallen for this; I did not know what to expect when we had Jamie, but I did expect that I would have “lowered expectations” for him. What I've found, though, is that I have to keep moving the goalposts— or, more accurately, that Jamie keeps moving the goalposts for me. Now, it's true that Jamie doesn't play the guitar. I'll give Peter Singer that much. But Jamie's interest in Star Wars and *Galaxy Quest* has given him an appreciation of science fiction, just as his fascination with Harry Potter has led him to ask questions about justice and injustice, innocence and guilt. (We are just finishing the final book in the series, and for the past few months Jamie has been asking whether Harry would “turn into Voldemort” in the end. It is an entirely appropriate, indeed profound, question, which for obvious reasons I will not answer

tonight.) Jamie is learning a foreign language, having mastered the “est-ce que tu” question form in French and being able to charm young women at the cheese counters of French supermarkets by saying “je voudrais du fromage de chèvre, s’il vous plait.” I confess that neither of us has the least interest in chatting about the latest Woody Allen movie; but perhaps Professor Singer will someday be interested to learn that Jamie and I have had a running conversation over the past five years about the film *Babe*, which introduced Jamie not only to the question of whether it is right to eat animals but also to the fact that there are various theories out there as to why humans eat some animals and not others. (The dogs, for example, believe that humans only eat stupid animals, and that “pigs are definitely stupid”; the duck, however, believes that humans will not eat “indispensable” animals such as cats and roosters, and decides that he will be spared if he learns how to crow at daybreak.)

But I’m getting ahead of myself. Twelve years ago I published a book about Jamie, our experiences with him over his first four years of life, and about (yes) our expectations for him. Jamie knows there’s a book about him, he knows that people read about him, and he’s promised to help me write a followup book after he graduates from high school. When it comes to talks like this, Jamie knows the drill: a few years ago I told Jamie that I would be speaking about him to a large roomful of people and that one of the stories I would tell would be the story of the pizza in the microwave. The pizza was wrapped in tinfoil, and the results were kind of scary. Jamie was a little uncomfortable with that, but I assured him that it was really a good story about how he learned to become more independent; when he saw smoke billowing from the microwave, he ran to tell me he needed help, and now we know always to take things out of the tinfoil and put them in the microwave for 22 seconds. But on this occasion a few years ago, I asked Jamie if I could

also tell the story of the day he was sad, or whether it was private; Jamie told me it was private, and it has remained private ever since. The question of what is public and what is private is awfully obscure and abstract, but, as we all know, it determines what we can say and what we can do and what we can wear in various locations from the living room to the locker room; and Jamie and I are working it out as we go.

Jamie has reached milestones his mother and I didn't even imagine for him: he plays golf with me and may be the most patient golfer I've ever known; he loves Renaissance art and asks to go to Barnes and Noble to buy books on da Vinci and Caravaggio; and he knows more about sharks than almost anyone who doesn't study them for a living. And I want to stress that most of Jamie's milestones are of his own devising; we never sat down, Janet and I, and decided that we wanted to have a child with Down syndrome who could do and know all these amazing things. We're not "pushing" him; we're not the helicopter parents from hell. But we do listen carefully when Jamie expresses enthusiasm for something, and whenever we hear it, we try to encourage that enthusiasm all we can.

And it really is just a matter of listening. Seven years ago, when Jamie was just ten, I heard him muttering something in his room, something about three and seven making twenty-one. "Jamie," I said, walking down the hall to his bedroom, "were you doing multiplication in your head?" He became shy, as if I'd caught him watching Hannah Montana on YouTube. "No, that's great," I said. "Hey, what's four times six?"

"It's *too hard*," Jamie replied, and then added, almost to his own surprise, "twenty-four."

That pattern has repeated itself time and again. In fourth grade his class did a social-studies unit on Japan; Jamie responded by becoming fascinated with Mount Fuji—

and by the very fact that the Japanese use a writing system radically different from ours. So fascinated, in fact, that when he went to State College's only passable Chinese restaurant that year, he asked his waiter how to pronounce the Chinese characters on the menu, beginning with "ching ding," or "Golden Wok," the name of the restaurant. (I should add that there are times when we have to rein in Jamie's curiosity— as when he asks waiters how to say thank you in Hindi just because they're working in an Indian restaurant, or when he asks waiters when the restaurant first opened for business. That's a very recent concern of his, and not every waiter and waitress he encounters happens to share it.) But that's what got Jamie interested in languages— and that's what gave us the idea that, after he was briefly introduced to Spanish and French in sixth grade, and loved the experience, he might actually want to *take* French in seventh grade. (It was his choice. Unfortunately, that year he was assigned to a paraprofessional who was kind of withdrawn and depressed, and didn't much care for the idea of helping a child with cognitive disabilities who was taking mainstream classes in French and Science . It was just bad luck all around, but over the past two years we've made our own good luck with Jamie's high school French classes.)

In eighth grade, he took classes in art and music. Now, most of the people I speak to think, "hey, that's great— classes that help Jamie express himself artistically, as best he can." But that's not what got him interested in art and music: these were classes in the history of Western art and music, and they asked Jamie to understand and identify medieval, Renaissance, baroque, Romantic, and modern forms of art and music. I promise you, this was not on his parents' agenda. We were not pounding on the doors of his classrooms demanding that he be acquainted with the works of Johann Sebastian Bach or would we sue, sue the entire school district. We simply noted the fact that one

day, as he was getting ready for bed, Jamie said, unprompted, “Stravinsky! That’s another great composer we didn’t mention!” Janet and I responded by going to Barnes and Noble and getting him one of those “Fandex” cards [demonstrate] devoted to composers since Vivaldi. Now, Jamie doesn’t necessarily like *listening* to these composers— he’s a teenager, folks, and his tastes range from the Beatles to the alternative-rock world of Ted Leo and the Pharmacists and the band known as British Sea Power. But Jamie now has Fandex cards for painters, African countries, dog breeds, and US states. And he’s managed to memorize a great deal along the way: I believe he now knows all state capitals and most of the major college football and basketball teams in the country. It’s as if he has his own personal Fandex for these things, a catalog of information his remarkable mind can unfold at will.

But let me switch gears and talk about Jamie in a somewhat different register. This story isn’t about how much he knows or how good his memory is. This is a story about what he’s like.

Traveling with Jamie is like nothing else in the world. He loves everything about traveling— the packing, the driving, the airport, the rental car, the hotel, the actual destination (wherever it may be), and the pool (for there must be a pool). And as he’s gotten older and more mature, he’s learned to tell stories about traveling— like the story about the time he had to have a Coke at 7 am in the Dublin airport because there was no milk for sale anywhere, or the time (a few days later) when his parents forgot to pack his retainers and left them in a Dublin hotel. I’m going to tell a story that speaks to some of the challenges and rewards of traveling with Jamie; it’s a story he’s familiar with, and we’ve agreed that it is not private. Two years ago we traveled to Seattle and Vancouver for a meeting of English department heads. (I’ve never been the head of a department

and never will be the head of a department, but I was asked to go for some other reason.) We flew into Seattle and then drove two hours to Blaine, Washington, on the Canadian border, and then took a day trip to Vancouver. On our way into the city, Jamie announced that we were “running out of film.” I assured him that he was quite wrong about this, because I knew that there were twelve exposures left on the disposable camera we’d bought the day before. But when we sat down to lunch al fresco at a little restaurant across from the Capilano Suspension Bridge, I watched him drinking his soda and said, “you look so cool like that— hold on and I’ll take your picture,” whereupon I discovered that there was, in fact, no film left in the camera.

“We’re running out,” Jamie said, just as he had noted an hour or two earlier.

“Ah, I see,” I replied. “You mean that when we crossed the border into Canada and I left you in the car while I went to get Canadian dollars, you took all the pictures in the camera? And then you told me we were running out of film?”

“Yes,” Jamie said, with a wry smile. And then: “Michael, are you gonna sigh?”

“No,” I sighed, “we’ll just get another camera, you ignatz.”

“Say, ‘oh, what am I gonna do with you,’” Jamie demanded. This is a line from *Curious George*, but Jamie finds it appropriate at such moments.

“Yes, Jamie, that was a very *Curious George* thing to do, to use up all the film and take all the pictures in the car. What am I gonna do with you?” He merely grinned and rubbed his hands together.

At the end of lunch, I told him we both had to go to the men’s room before we went to the bridge. But he didn’t want me to go with him. He insisted, instead, that he would go into the restaurant alone and find the bathroom all by himself. I approved, reminding him to ask a server if he couldn’t find it right away, and I told him I would wait for the check. He

came back in a few minutes, hands washed and everything, all set to go. But the check still hadn't arrived, even though we were now one of only two parties in the place. "Let's go," Jamie insisted. "We're still waiting for the check," I replied. "Why?" he asked. "I don't know why," I said. Finally, our server arrived, and I had the credit card ready for her, and soon we were all paid up. I told Jamie to wait at the table while I went to the men's room. When I returned, Jamie was waiting very patiently . . . but Jamie had an odd canary-eating expression on his face, and I thought it might be a good idea to check the check. Sure enough, on the \$23 bill for lunch, Jamie had written, just under my "\$30," the figure "\$90." I gave him a sidelong look.

"Say, 'I wish you wouldn't,'" Jamie said.

"I wish you wouldn't," I dutifully replied. "You cannot leave ninety dollars on this check. It is too much money." Jamie grinned again. "No, really. Don't do that, please. It will make our server very confused, and besides, thirty dollars is really enough." Since that day, I've ascertained as best I can that Jamie understands tipping. He's just not clear on the details. It's something we're still working on.

But when it was time to come back home and grab our redeye flight from Seattle to Pittsburgh, Jamie was quite a different young man. He was exceptionally good about getting ready for bed at the airport, even though this initially made no sense to him. He asked only for a glass of chocolate milk before he had to brush his teeth, and when I explained to him that most of the shops and stores in the Seattle-Tacoma airport were closed, he said "we should ask," and promptly stopped a person at random: "do you know where there is chocolate milk?" (I explained to Jamie that this somewhat nice man— he merely half-smiled at the question— did not work at the airport.) We found a Starbucks shortly thereafter, and Jamie decided he would wait on a bench near security while I got

some water for me and some chocolate milk for him. I was being served just as they began to close up shop at 10 pm: I knew it would cause Jamie some distress to see his father being trapped in Starbucks behind the metal grate (aha! that's how they "recruit" their employees!), so I looked back, and sure enough, there he was on his bench with his hands to his cheeks and his mouth open in the "Home Alone" position. I gave him the thumbs-up to let him know I could get out again, though, and came back in a minute or two with his freshly-mixed chocolate milk. And then Jamie did something that led me to teach him a new word for describing what he's like: conscientious. When we learned that our plane would be an hour late, I told Jamie that we would have to wait until after midnight before we could board. We set up shop on a little couch-like structure right by our gate, and Jamie played Harry Potter on the laptop for a bit. At eleven I asked him if he wanted to stretch out with his pillow on the couch. "Are you sleepy?"

"Um, a little bit," he said, "not that sleepy."

"You're not that sleepy? I am very sleepy," I admitted.

"You sleep," Jamie suggested, "I will play Harry Potter right here."

"Oh, thank you, Jamie. That's very sweet. But I don't want to fall asleep and miss our plane." I knew there was no chance of him wandering off, but still, sleeping on the job is sleeping on the job.

"Michael! You will not miss the plane!" Jamie said. "I will tell you when it comes."

I looked at him with genuine surprise. "You will tell me when the plane comes?"

"Uh huh," he said. "Now you sleep right here."

Well, one of the side benefits of all this travel is that Jamie learns new ways of being independent, like finding restaurant bathrooms by himself. But this seemed a bit much. On the other hand, what could possibly happen? I would be right next to him, and

I certainly wouldn't sleep so heavily as to be unable to snap to attention if a passing lunatic tried to mess with him in some way. And I would just close my eyes for a second. . . .

But . . . how would he know when the plane arrived. . . .

Twenty minutes later, Jamie jostled my elbow. "Wake up, Michael," he said gently. "Our plane is here." And sure enough, the passengers had just begun to disembark. Jamie had been watching carefully the whole time, even while dodging dementors and imps and skeleton men in the dungeons of Hogwarts. Because, you see, he is very conscientious. Also observant and mature and independent.

One of the reasons I tell this story *to Jamie* is that I want to enhance his own sense of his independence— and to remind him of how far he's come. He and I had a very serious conversation about five years ago after he'd asked to do eight or nine things in the course of an afternoon— which would be fine, right, it's what kids do, except that when Jamie gets it in his head that he's going to do eight or nine things, he makes a mental checklist and gets very disappointed if every item isn't checked off by the end of the day. So I told him that he was very good at math and that he has a great memory and all, but really needs to understand time better. "We need to work on that," I insisted, "so you can understand how long things take and how much time we have to do them." And it wasn't just a matter of knowing that it takes an hour to go bowling, for example; he also didn't know how to use temporal markers to indicate past action [explain]. Now, by contrast, he has a watch and keeps very careful track of what time it is, and he is exceptionally careful about remembering what things happened to him in what year and how old he was at the time. I'm hoping that he can make similarly impressive progress understanding an abstraction like money, although I have to say that over the past few weeks, I'm not convinced that anyone really understands "money." [Hermione and the Time-Turner.]

The other crucial factor in all this, of course, has to do with Jamie's understanding of narrative— which has been enhanced immeasurably by his love of Harry Potter. One example, I hope, will suffice. One night I was reading *Harry Potter and the Half-Blood Prince* to Jamie just as he was dropping off to sleep. Our routine goes like this: he climbs into bed around a quarter of ten (being a teenager and all), and even though he's capable of falling asleep the minute his head hits the pillow, he is so eager to hear the evening's Harry Potter installment that he keeps one eye open and fights for consciousness as long as he can.

We reached a scene in which the young Dumbledore visits eleven-year-old Tom Riddle (that is, the young Voldemort) in the orphanage in order to inform him that he is a wizard and extend him an invitation to Hogwarts. It's a dramatic encounter; Jamie raised his head off the pillow and gasped at Tom's initial reaction to Dumbledore's invitation, and stayed awake for another couple of pages. But before we got to that point, I read the following passage:

The orphans, Harry saw, were all wearing the same kind of grayish tunic. They looked reasonably well-cared for, but there was no denying that this was a grim place in which to grow up.

I decided to say a few words about the orphanage, and about Harry's moment of sympathy for the boy who grows up to become Voldemort. "Did Harry have a happy childhood when he was growing up?" I asked. Jamie shook his head no. "He had the Dursleys," he said. I pointed out that Harry and Voldemort are similar in that they grow up without parents, and that the kids in the orphanages are there because they have no parents either. And I mentioned that Jamie might remember the orphanage in the movie *Like Mike*, which just happens to be in Jamie's video collection.

“Or *Free Willy*,” Jamie suggested. “Yes, that’s right,” I said with some surprise. “*Free Willy* is also about a kid who is growing up without parents, and who has stepparents, and he has trouble getting used to his new home.”

“Or *Rookie of the Year*,” Jamie said. “Not exactly,” I replied. “In *Rookie of the Year* Henry has his mother, but his mother’s boyfriend is a creep, and we don’t know where his father went before he was born.”

“*Mrs. Doubtfire*,” Jamie offered. “Nope, that’s about parents who are divorced and live in different houses,” I said, “but still, in *Mrs. Doubtfire* the father misses his kids and wants to see them, so dresses up as a nanny.”

“What about *Babe*?” Jamie asked.

“Oh yes, that’s a very good example,” I told him. “*Babe* has no parents, and that’s why he is so happy when Fly agrees to be like his mother.”

“And Rex is like his father,” Jamie added. “And Ferdinand the duck is like his brother.”

Why, yes, I thought—Ferdinand is like his brother. Hey! Wait a second! Who knew that Jamie was thinking, all this time, about the family configurations in these movies? And who knew that Jamie knew that so many unhappy families, human and pig, are alike?

[*Spiderwick Chronicles*, *Night at the Museum*— “also about divorce,” says Jamie.]

And now to return to Peter Singer, and the little matter of what we can and can’t expect of children with Down syndrome.

In the opening pages of *Life As We Know It*, I wrote that most of my time with Jamie— that is, when I’m actually with him, doing stuff— is lived pretty much moment by moment. And I wrote this specific passage just under ten years ago:

Occasionally it will occur to Janet or to me that Jamie will always be “disabled,” that his adult and adolescent years will undoubtedly be more difficult emotionally—for him and for us—than his early childhood, that we will never not worry about his future, his quality of life, whether we’re doing enough for him. But usually these moments occur in the relative comfort of abstraction, when Janet and I are lying in bed at night and wondering what will become of us all. When I’m with Jamie, by contrast, I’m almost always fully occupied by taking care of his present needs rather than by worrying about his future. When he asks to hear the Beatles because he loves their cover of Little Richard’s “Long Tall Sally,” I just play the song, sing along, and watch him dance with delight; I do not concern myself with extraneous questions such as whether he’ll ever distinguish early Beatles from late Beatles, Paul’s songs from John’s, originals from covers. These questions are now central to Nick’s enjoyment of the Beatles, but that’s Nick for you. Jamie is entirely *sui generis*, and as long as I’m with him I can’t think of him as anything but Jamie.

The clear implication here— and you don’t have to be a literature professor or a famous utilitarian philosopher to see it— is that a child with Down syndrome will never have the intellectual capacity to understand the Beatles’ oeuvre, or even to understand that some songs preceded others, were written by different band members, and so forth.

Well, this is overdue, but I owe Jamie one enormous apology: I couldn’t have been more wrong. Over the past twelve years Jamie has become so fascinated with the Beatles that he’s memorized almost the entire songbook. He’s not terribly familiar with late George Harrison ephemera like “The Inner Light” and “Old Brown Shoe,” but that’s no real loss; besides, in every other respect, his knowledge of Beatles music verges on the preternatural.

It started when Jamie was about eight or nine, when he was fascinated with “Being for the Benefit of Mr. Kite,” and “Come Together” (he still gets a kick out of “juju eyeball”), whereupon I explained to him that John had written those songs and that John liked to play games with words. Jamie was so thrilled with this news that he demanded to know what else John had written. So I went back over the Beatles’ output, and found to my surprise that John had written about two thirds of the originals on the Beatles’ first four records. Before I knew it, Jamie had memorized “the Johns,” as he puts it, and proceeded to master the other three as well (for Ringo, we go by the songs he sang, not just the two he wrote). Then Jamie wanted to know who wrote “Honey Don’t” or “Roll Over Beethoven” or “Anna.” Then, as we made him presents of each CD, he began to understand which records contained which songs. Then, as he began to ask which came first, I bought him one of my favorite books of rock criticism, Roy Carr and Tony Tyler’s *The Beatles: An Illustrated Record*. By now, Jamie had a sense of the year-by-year, record-by-record trajectory, and, as we bought him more Beatles books, we learned that he has an astonishing memory for other things as well.

“Remember when the Beatles were in the Bahamas?” he asked one day.

“Uh,” I said, trying to think of Beatles’ world tours, “I don’t think they ever played in the Bahamas.”

“No, in *Help!*” he insisted, and proceeded to show me one of the pictures in yet another Beatles coffee-table book we’d gotten him. Yep, there were the Beatles in the Bahamas. Score one for Jamie. Now Jamie has a whole quiverful of such questions. Remember when the Beatles had a pillow fight? Remember when John disappeared in the bathtub? Remember when Ringo was combing his hair in the bathroom at Shea Stadium?

So when he's bored, or when we're trying to kill time in long lines or on long trips, Jamie sometimes asks me to "do all Pauls," or whomever, and I will proceed to pick random tunes from here, there, and everywhere. I'll sing about two bars— "Close your eyes, and . . ." and Jamie will immediately jump in and say "With the Beatles. 1963. Next!" And I'll say, "let me think," and he will mock me, and I'll sing "Martha, my dear . . ." and he'll say "White Beatles. 1968. Next!"— and this can go on, as you might imagine, for some time, until my own memory is exhausted. On one of our trips, as we waited fifteen minutes by the baggage carousel, we got through about sixty or seventy of these, much to the amusement and/or annoyance of our fellow travelers, one of whom asked, "Did you already do 'Norwegian Wood'?"

What makes this especially curious, to me, is that he's not just cataloguing information and spewing it back; he's got everything cross-referenced somehow, and he never fails to name songs I've forgotten. But even more astonishing is his ability to associate specific words with specific songs. When Jamie was in fifth grade we were doing the words on his spelling list, and when he came to "through" he sang, "Through thick and thin she will always be my friend." The word "you're" was met with "you're gonna lose that girl"; "picture" with "picture yourself in a boat on a river." Part of his homework required him to use his spelling words in complete sentences, and we told him that he can't always just place them in Beatles songs, that he has to think up his own sentences. But if you'd asked me in 1994 whether I imagined that I would ever have to issue Jamie an injunction like that— stop quoting Beatles lyrics in your spelling-word sentences— I probably would have given you a very dirty look.

I draw from this what I hope is a useful conclusion. it might be a good idea for all of us to treat other humans as if we do not know their potential, as if they just might in fact

surprise us, as if they might defeat or exceed our expectations. It might be a good idea for us to check the history of the past few centuries whenever we think we know what "normal" human standards of behavior and achievement might be. It might be an even better idea to look at the recent history of early intervention and full inclusion, to see how our expectations for people with cognitive disabilities, and our social practices with regard to people with cognitive disabilities, have affected the lives of people with cognitive disabilities. As Jamie reminds me daily, both deliberately and unwittingly, most Americans had no idea what people with Down syndrome could achieve until we'd passed and implemented and interpreted and reinterpreted a law entitling them all to a free appropriate public education in the least restrictive environment. And most broadly, it might be a good idea to expand the possibilities of democracy precisely because democracy offers us unfinished and infinitely revisable forms of political organization that stand the best chance, in the long run, of responding adequately to the human rights of the unpredictable creatures we humans are. That might be one way of recognizing and respecting something you might want to call our human dignity.

And so, Jamie, I admit it. Even when I was trying to represent you to the best of my ability when I wrote *Life As We Know it*, I underestimated you. I was wrong, and I apologize. And through thick and thin, I will always be your friend.