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THE CHRONICLES OF BEN

For 12 years, their autistic son had been part of the family. now they had to say goodbye.

BY DAVID ROYKO

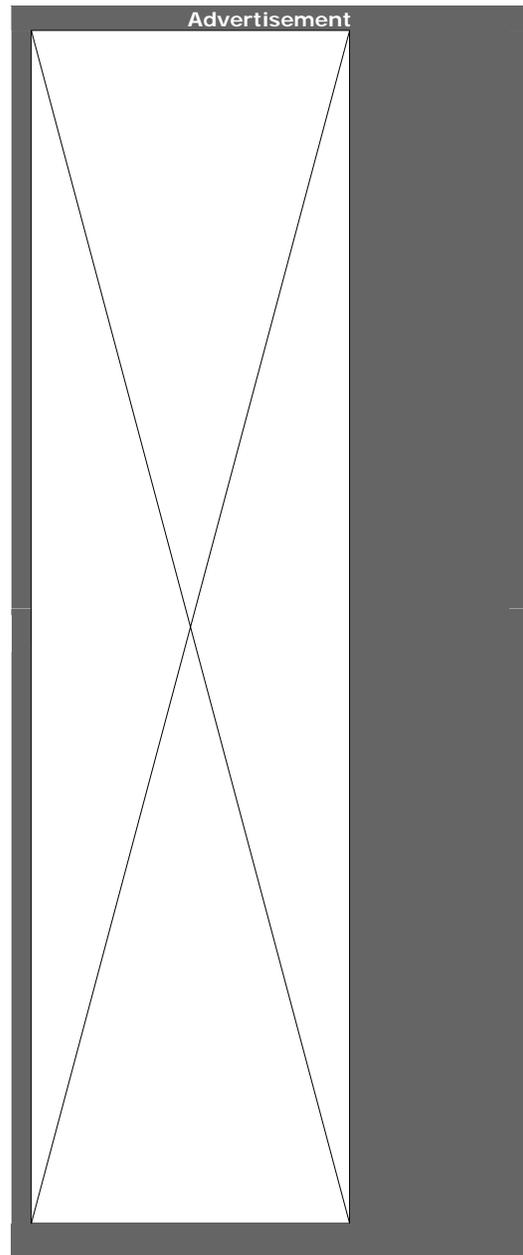
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Ben loves babies, especially when they are in distress. He smiles and says, "Baby cries." We don't know what it is that he finds appealing about a sound that sets most other people's teeth on edge, but it's unlikely he enjoys the baby's anguish. Ben's severe autism blinds him to the emotional meaning of the tears, leaving only the novel and entertaining sights and sounds of the baby's performance.

"Baby cries," he says to me as he stares with interest at my own performance, as I sit sobbing next to him on the couch. Ben's gaze shifts between me and Barney on TV, singing "I love you, you love me . . ."

"It's OK, Ben," I say between gulps of air. "Daddy's just feeling very sad." I'm not sure whether Ben cares about the explanation, but he is riveted until the next section of Barney begins, and my tears are trumped.

The past 24 hours have been grueling, but it's the past dozen years that are really hitting me. Ben had been a "difficult" baby ("Baby cries" indeed), and the diagnosis of autism that came as a vile birthday gift the summer he turned 2 suggested that things wouldn't get easier for him, or us--Mom Karen, Dad Dave, or Ben's



non-autistic twin brother, Jake.

Soon after the diagnosis, I saw a TV episode in which the mother of an autistic boy was in an ER because her arm had been inadvertently broken by the growing lad. The doctor discussed residential placement, her broken arm being the last straw. I remember wondering if that would be us someday.

A decade later, Ben has yet to break any arms, but Karen's are full of bruises, scratches and scars from old scratches. She's 5 feet 3 inches tall, and Ben already tops 6 feet and 250 pounds (my DNA's fault--I'm 6 feet 6 inches and weigh more than 300 pounds). Developmentally, he is a toddler. Physically, he is a man, a BIG man, and still growing. Most of the time, Ben is as sweet a creature as you have ever known. He has a radiant smile and can be unusually affectionate for an autistic boy. Enormously lovable, with a delightful personality. Those who work with Ben tend to adore him.

But as he has grown in stature, those moments when he is not a sweet creature have become more difficult, if not dangerous. Several years ago, two of Ben's therapists met with Karen and me because they felt it was time to pursue residential placement. They felt that Ben would make more progress and better fulfill his potential in a residential setting. They also felt that waiting and watching Ben grow bigger without parallel growth in his socialization would work against a good placement for him, narrowing his options.

We didn't disagree. But we didn't do anything about it. To even think about banishing our sweet Ben to who-knows-where was enough to induce nausea, especially for Karen. So what if her body was resembling a punching bag? Nobody ever said parenting would be easy.

The truth is, I was ready for Ben to go to residential treatment a couple of years before Karen, but my arguments, anybody's arguments, were no match for Karen's maternal instincts. She was determined to see Ben through his childhood at home, hoping he could make it to age 21 before leaving. I had resigned myself to this, deciding that if we had to wait till then to get our lives back, so be it.

What made it especially hard to think about putting Ben through the trauma of moving away was that he is such a sweet boy, even when naughty. The other day, Karen went to check her e-mail, letting Ben out of her sight for two minutes, which is always a risk. When she walked into the kitchen, she found that Ben had gone to the fridge, removed a dozen eggs, and smashed each one on the kitchen floor.

Then he looked at Karen and said, with a little smile, "Mama, do you love me?"

Karen realized immediately that Ben was acting out a scene from one of his favorite books, about a girl who keeps testing to see if her mother will always love her, no matter what devilry she commits, including breaking eggs.

So when Ben, standing amid yellow yolk and shattered shells, asked, "Mama, do you

love me?," all Karen could do was answer with the book's refrain, "I will love you, forever and for always, because you are my Dear One."

So, we soldiered on, our protective shells of denial growing thicker as Ben grew larger.

By the summer of 2005, the situation had deteriorated enough that we agreed, still in theory more than practice, that we shouldn't wait any longer. Ben had just wrapped up 5th grade, and for two years he had been blessed with an extraordinarily gifted and seasoned teacher and a classroom staffed with talented and experienced aides. He had made great strides, especially regarding toileting, with "accidents" becoming rare at school and less frequent at home.

But summer brought trouble. Ben does best when busy. I have often thought that the schedule that would make him happiest would be 365 days of school. When Ben's been busy all day, he's relaxed at night. When he's out of school and bored, he is grouchy, and the world around him knows it. Making matters tougher was that, come September, Ben would be in a new school, a junior high with new kids, a new teacher and new aides. For Ben, transitions, in a word, suck.

Things did not go well in his new school the first weeks. His toileting had regressed badly and he was coming home with soiled clothes in his back pack. The notes from school suggested that the days were rough: He wandered off school grounds, even though he was being shadowed by his aide, crossed the street, lay down in a driveway and refused to get up; he ripped apart the ceiling of the taxi that was driving him from school. Even worse, we received word that Ben had scratched his teacher and tore her blouse.

Then she quit. We were assured by school officials it wasn't due to Ben.

From late September to January, Ben's class had a stream of substitute teachers, different ones every day of the week, all doing their best. Come January, the class had a new 6th grade teacher, but Ben was well behind where he'd left off after 5th grade. He also was growing ever bigger.

His behavior at home wasn't any better. His sleeping had slipped back into a pattern of frequent awakenings, periodic early-rising (3 a.m.), and refusal to go to bed in the evening. The only time Ben doesn't need direct supervision is when he is asleep, meaning if he's up, one of us is up.

Then there's the excrement. And more excrement. In his pants, in his bed, on the couch, in the car, on him, on us. That's what finally pushed Karen over the edge. We are a two-minivan family, with Karen giving me the older minivan when we get a "new" used one for her. Karen left the dealership in our old van to pick Ben up from therapy while I finished up our new purchase. There is a special pleasure in driving a newly-bought vehicle home. Everything about it is fresh and exciting, and I was looking forward to briefly exulting with Karen as I pulled up to our house.

The sight that greeted me brought me back to reality. Our old van was in our driveway, all the doors open, with Karen next to it. Ben was lying on the van's floor. His pants were off, and he refused to budge. A neighbor had already come and gone, his offer of help heartfelt, if ultimately futile. By the time Ben decided to move, he'd left a wake of feces behind in the minivan.

Ben isn't always that way; in fact, we can go months without experiencing his more challenging behaviors. The cycle of good and bad phases is what allowed us to dream, in the best moments, that he would "grow out of" these behaviors. But autism, a neurological condition that impedes growth in social interaction and communication skills, is also known as Pervasive Developmental Disorder. By definition, autistics don't naturally grow out of, or into, things the way typical kids do. So Ben's phases come and go, and his current phase included car befouling.

A few days later, with Karen behind the wheel, Ben decided to anoint the new minivan. He undid his seatbelt, lay on the floor, and did what he does. This time, however, Ben also turned his attention to the driver's-side sliding door. In the old van, the safety locks were always engaged. We thought we'd done the same with the new van, but we were wrong.

Karen drove with one hand on the wheel, the other reaching behind her to hold the sliding van door closed as Ben multi-tasked, trying to open the door while lying on the floor and filling his pants. With a newfound lack of ambivalence, Karen said to herself, "It's time for residential."

But first, we had to convince our school district that it was time and that the district should pay for it. An Individualized Education Program (IEP) staffing was scheduled for Monday a few weeks hence. IEP staffings can resemble battle scenes. On one side, parents are armed with experts and lawyers, determined to wrest from the school district services they believe their child is entitled to. On the other side are district experts and lawyers, determined to spend tax dollars in what they deem a responsible manner.

For us, however, IEPs had been, with few exceptions, lovefests. Ben's are not subtle problems. The nature of his autism screams, "I need help!!!" At our first IEP, before kindergarten, we had our lawyer there, and Ben got what he needed--an appropriate special-needs classroom and teacher, a one-on-one classroom aide and a taxi ride to and from school because he would be a serious management issue for a bus driver and other kids. The past seven years of Ben's IEPs were largely uneventful. Until now.

he weekend before the IEP served as our pre-game warm-up. Ben had been increasingly aggressive in recent weeks, and not necessarily when angry or unhappy. You could be sitting with him, looking at a book or a TV show, and before you could react, his hand would dart out and put a deep scratch into your arm, or his elbow would land a hard blow to your chest, or his arm would snap back and smash your nose and send your glasses flying, or his head would butt your head or shoulder. These are not involuntary motions, but deliberate actions, meant to--who knows? Meant to inflict pain? Meant to be playful?

Meant to elicit reaction? All of the above? We just don't know, even if we sometimes think we do.

On the Sunday evening before the IEP, Phil, our tax guy, had come to help with our returns. Then Tina, a college student who had started working with Ben in-house, arrived, allowing Karen to run out and pick up some prescriptions.

As Phil and I discussed Ben's medical expenses and deductions, Tina called me upstairs. Choking back tears, she said, "I don't know what I'm doing wrong." Our 250-pound Benny had hit her. She changed activities, but he whacked her twice more. I assured her that it was nothing she was doing wrong, that we have all been on the wrong end of Ben's aggression, and that he was in a nasty phase right now. Then I let her go for the night, put Ben in front of a video, and went back to Phil, assuming, correctly, that we had seen the last of Tina.

By the time Ben was tired enough for bed, it was 11. Jake was already in his room, trying to get to sleep. We brought Ben up to his room.

Recently, Ben had wanted to lie with me at bedtime as I watch TV, especially when basketball was on. When he would start to doze, I would have him move to his room. Usually, this began at 8:30. On this night, it was late, and we were ready for sleep ourselves. But Ben decided he wasn't ready.

I stood in his doorway, telling him, "It's time for bed." Ben tried to push me out of the way, saying, "No bed." stood firm. "Yes, bed," I said.

Then the scratching, elbowing, head butting, and biting began. I immediately had three bleeding scratches on my arm. I slapped his hands away as best I could, and then held his arms, telling him, "No Ben, quiet hands."

He threw his entire weight into me, knocking me against the wall. I shoved him into a sitting position on the edge of his bed and quickly walked out, pulling the door closed behind me and holding the knob, since we don't have a lock on his door. He hollered and slammed against the door a few times--I could see the wood bulge. Then I heard the items on his dresser hit the floor. He was stamping his feet, and screaming with inarticulate rage.

Each time Ben quieted down, I would crack open the door, only to see him standing, ready to lunge again, or kneeling, ready to lunge again. Quickly, I would try to steer him toward the bed, and then defend myself from the blows and bites and retreat again to the other side of the door.

After an hour, I heard Jake say something from his room. It has always amazed me that Jake can sleep through Ben's middle-of-the-night rages. This, however, was a particularly loud and long one.

Jake's a bright, gregarious boy, and even though Ben's a very hard child to interact with, Jake is a devoted, protective brother. As Karen lay down alongside Jake to comfort him, he expressed intense sympathy for Ben. "I remember what it's like to be afraid to go to sleep," he said. Then he said, "Is Dad hitting Ben?" I am not a parent who hits, but the sounds from Ben's room had made Jake wonder, and worry. He began to cry.

As I stood outside Ben's room at 12:30, holding the knob, watching blood run down my arm, listening to Ben scream and Jake sob, I found myself fighting the urge to phone one of the IEP team members and say, "Listen to this and tell me Ben doesn't need residential."

The question could reasonably be asked, "Why didn't you just let him sleep in your bed?" On many a night, that's precisely what we have done--given in. But it was late, he was tired enough to be dozing on the couch downstairs, and dammit, we wanted to go to sleep, which couldn't be done with Ben in the same bed. When the tantrum began, I didn't think he had the energy to sustain it for more than a few minutes. By the time it had gotten to this nuclear level, giving in wasn't an option. His aggression would carry over, and we would be reinforcing and rewarding the behavior.

What probably brought Jake to tears was hearing me say to Karen, "I'm starting to think we might have to call 911." I was concerned that Ben would smash his bedroom windows (he's done so accidentally more than once, but not while raging). Maybe a 911 call would bring paramedics with a sedative to inject. I kept listening for the sound of shattering glass, but it never came. At last, close to 1 a.m., the room got quiet. I looked in.

Ben was asleep, knees on the floor, head on the bed. I was wrung out, on the verge of tears myself, but relieved it was finally over. It wasn't. When I walked in, my nose told me that Ben had a load in his underpants.

Excrement can serve as Ben's trump card. The last word. As one of his therapists said, "The message is clear: [Expletive] on you!" Ben has virtually full control over where and when he goes, and total awareness of what the bathroom is for. He knows that when he's in a situation he doesn't like, such as being made to go to bed, all he has to say is "bathroom" and he's whisked away to a toilet. Alternately, he knows how to change the scenery by not using the toilet. Since he doesn't know the meaning of embarrassment and feels nothing in the way of social pressure, a pantsload has few drawbacks while guaranteeing an interactive trip to the bathroom or the bathtub. Ben's "accidents" are really anything but. They are decisions. As Ben knelt on the floor, dozing with his head on the bed, the contents of his underwear delivered his message loud and clear.

We got Ben into the shower, and much to our relief, he went to sleep immediately afterwards, as did Jake. Not surprisingly, it took Mom and Dad quite a bit longer to drift off.

A couple of months earlier, Karen had discussed with Jake the reasons why Ben would have to go live in a residential treatment and education facility. After a while, Jake said,

"Mom, are you trying to convince me or yourself?" Jake had been the one person within our circle of friends, family and therapists who had not yet signed off on the idea, relating to Ben in the acute way only a twin brother can.

As I drove Jake to school the next day, I asked if he disagreed about the need for Ben to move to a residential facility. "No, not anymore," he said. "After last night, I agree. He needs it."

When we brought Ben to school, his teacher greeted us and took Ben to his class while we made our way to the conference room. Past IEPs always began with some version of "Who is Ben?" and "What are your dreams for Ben?" We didn't have time for that today, and since most of the 15 or so people there knew very well who Ben was, there was no need.

Our concern at this point was nothing less than survival. As he grew larger and stronger, the potential for danger to us grew, which meant danger for Ben. Not long ago in our area, an autistic man in his 30s, living in a group home and having what sounded eerily like one of Ben's tantrums, was killed by police intervention.

We described how things had gotten to the point where the only appropriate solution, as we saw it, was a residential placement. It was what he needed, desperately, and now, before any more time was wasted and he grew larger and his options narrowed. If we didn't act now, his future, already hugely compromised because of his autism, would be even more so. By way of example, I described the previous night's adventure, with my scabby arms providing the multimedia portion of my presentation. I genuinely thought there would not be much more to discuss.

Karen and I could not believe our ears when one participant said that she believed Ben's needs were being met in the classroom setting. For a moment, I didn't know what to say, but our lawyer did. She is one of those extraordinary people that you almost believe it was worth having an autistic child to meet. Almost. Besides being smart and overwhelmingly compassionate, she is non-adversarial, always choosing to negotiate instead of litigate, but she can play hardball if she has to. She was being honest when she said, "Look, you all know I don't play games, and I'm not saying this as a threat. But sometimes I have a kid where the needs are so obvious, and that is the case here. Ben needs a residential placement. Just so you know, if we have to, we will go through [litigation] and we will win."

Soon after that salvo, Ben's classroom teacher was pulled from the meeting. After a short time, a couple of others were called out, and then another. Something was up.

We went on with the meeting, growing increasingly incredulous that we were going to have to jump through hoops after all. If Ben isn't an open-and-shut case, then who is? What does a kid have to do to "need" a residential placement, I thought to myself--send someone to the hospital?

The first person to return to the meeting looked shaken, and spoke quietly. "Is it Ben?" I asked.

It was Ben. And he'd just sent someone to the hospital.

Karen and I looked at each other. We didn't know whether to laugh or cry.

Ben was having a rough moment. By the time it ended, one aide had a bad scratch, and another had been bitten on the leg so hard that, though Ben's teeth hadn't penetrated the fabric of her pants, she still had a bloody welt. She's the one who went to the hospital.

"Ben's doing our work for us," I said.

"I would say so," said the administrator who makes the decision, as she wrote her notes. "He needs residential."

If this had been a basketball game, I would have been running around jabbing the air with index fingers and hooting loud and long. Yes, we had "won." But what we'd just won was funding to send our sweet little Benny boy away from home. I felt overwhelming relief and a touch of queasiness. I imagined it to be similar to what a loved one feels when they win a huge settlement because of an accident that resulted in the loss of a husband or a child. It's not the kind of win that brings a victory party.

There's no denying it though: Ben had perfect timing.

I got home just before Ben was dropped off. He looked like he'd been through an ordeal. His skin was blotchy, and he seemed to have a slight bruise that might turn into a black eye. The blotchiness was probably from the strain of the tantrum, and the bruise was likely self-inflicted---Ben hits his face with the heels of his hands when frustrated.

But he was in a good mood. After dinner, we sat together on the couch, and he was his sweet self, smiling and snuggling close. We watched "Barney," a favorite of his for 12 years now. (Can you imagine 12 straight years of "Barney"? Autism truly is hell.) Barney began singing, "I love you."

Having won our case for residential, we knew it meant Ben's days at home were now numbered. We couldn't say precisely when it would happen, but within a matter of months, Ben would be moving out, likely for good.

Barney continued, "You love me . . ."

Watching Ben beaming with joy, it hit me for the first time: I am going to miss him so much. That's when my floodgates opened. "Baby cries," said Ben.

I know residential is what he needs, I know he needs it now, and I am relieved beyond words that it will be happening. But I cannot imagine what this will be like for him. How

confused and terrified will he be? How much will he miss his house, his family, his many routines, everything he has ever known? Will he wonder if he'll ever see us again?

I was enraged. Autism had already stolen so much from Ben and from our family. Now it was pulling off its biggest heist yet, robbing the mint of its gold: At age 12, Ben was moving out.

As I had told Ben, I was feeling very, very sad--a despair I hadn't felt since those first days after the diagnosis. Since then, we had spent years repressing, rationalizing, sucking it up and just doing what we had to do to get through each day. Now the finish line for this phase of our family's life had come into view, and, somehow, it seemed sudden.

At the same time, the enormity of this phase that we were leaving behind was sinking in. Autism had become the center of our existence. Our lives had revolved around it, and I am finding it hard to imagine a family life that isn't held to a close orbit around autism.

That night, Ben was remarkably cheery considering how little he'd slept the night before. As for the rest of us, we were drained. Karen and I anticipated an early night for Ben. Until then, he'd be happy to watch TV with us in the den. Which he did until dozing off-- at 4:30 in the morning.

Next week marks the end of Ben's first year living away from home, at the Oconomowoc Developmental Training Center. It's just 90 minutes north of our house, in southern Wisconsin, and we see Ben frequently.

As heart-wrenching as it sounds--if not plain sadistic--Ben had to go without us, cold turkey, for the first month. No visits. Face-to-face contact would only send him blasting off with hope that he was finally going back home, only to smack his head on the ceiling of his new reality when we left. Before he could see us, Ben had to get comfortable with the training center as his second home. One month sounded horrible, yet reasonable and necessary.

For us, that month was like stepping into an alternate universe. After years of adjusting everything to accommodate autism, it was only when it was gone that we came to understand how much it had become the core of our daily lives.

We could never let Ben out of our sight, so someone always had to be on "Ben duty." Going out meant leaving one parent home, or paying far more than typical sitter wages to one of the very few who could handle Ben while we waited for the cell phone to ring with a crisis. Autism meant unpredictable bedtimes, unpredictable nights and unpredictable wake-ups. Going places with Ben had become virtually impossible except to therapists and the like. At any moment, anywhere, anytime, there was a good chance Ben's bowels or bladder would bring the kind of event that most parents recount for the rest of their lives as their big parenting horror story, but for us was business as usual.

These and a thousand other aspects big and small were now history, or at least someone

else's problem. Ben is in a place where those issues actually can be solved through 24-hour behavioral programming that should eventually rewire his brain.

On our first night without autism, Jake had friends sleep over, which was good because it kept him from noticing the heavy silence and uncanny calm of the house. At 9:30, Karen and I, anticipating a stampede to the kitchen for a snack, called up to the boys, "Let's go get some ice cream."

We grabbed the dog, crowded into the van, headed to Baskin-Robbins and ate ice cream on the bench outside the store. For Jake, it was a first: He had never had the experience of a spontaneous trip with Mom and Dad and friends to get ice cream. It was our first "normal" experience as a family, the kind of normalcy most people take for granted, but for us was anything but normal.

On the second night, Karen said, "It feels like I've taken a muscle relaxant." If only it had been that simple.

We still miss Ben every day, sometimes achingly so. At the same time, every day without the tsunami of autism saturating the life of our family still feels like a vacation, even as we grow accustomed to a certain degree of normalcy. That Ben is progressing, and seems happy, allows us to truly enjoy our new life. If any good has come from life with autism, it is a deep appreciation for the everyday, a sense of the ordinary feeling extraordinary.

The other day, someone asked if we'd gotten used to this new life yet, and I said, "No, and I hope we never do."

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