Pets and People with Disabilities

By Aaron Johannes

Many things have surprised me in my work with self-advocates (people with disabilities who declare themselves capable of self-governing). One has been how connected they are to their communities and their insistence on finding ways to “give back.” Some folks have unimaginably enviable networks and schedules full of good works and are esteemed volunteers that organizations depend on. It would be interesting to do one of those studies about how many wage hours are contributed by volunteers with disabilities.

Another surprising thing has been their certainty that pets are dead-center in the middle of their networks: cats, dogs, birds, fish or snakes, they are clearly labelled “friends.”

I`m not sure why this was a surprise as when we`ve done planning with folks leaving institutions or moving from their family homes or a group home, to their own home, a thing that comes up a lot is the desire for a pet. Florence, at 60, finally got the apartment in the community that she`d dreamed of all her life, and worked harder for than anyone I`ve ever known has worked for anything, and at the top of her list was “a little black kitten with white feet .”

Shortly after, while visiting the SPCA, she fell for a big old mangy grey tomcat with one ear named Chester, and the one dream was replaced by a new one, but that`s a different (happy) story.

I am thinking this morning of our late dog, who passed away yesterday. Onyx came to us as a troublesome teenage rescue who’d had a rough time in kennelled isolation, first with a broken leg that required immobilisation as a puppy and then with kennel cough, a communicable illness that required more isolation. Most of this happened in a Vet’s office in a back-room kennel so she didn’t get a lot of attention that was not medical. When we met her she had spent most of the first nine months of her life alone in a cage. She had, as do many of the folks that we know, a champion. Our friend, Dr Mike the Vet, had
refused to euthanize her when her owners decided she was too much trouble because, a deeply spiritual person, he believed she was “a good dog looking for a home.” I’m not sure if he’d say it this way, but he believed she had a mission. We agreed to a weekend trial, she was perfect, and we called him to say she was now a member of the family, and thanks.

By the end of our first week with her we had huge misgivings about what her mission might be! She was the dog from hell. She was disobedient, purposefully malevolent, she ran away, she ignored us in a condescending way and if you told her she was a “bad dog” (which she was) she was obviously not interested in what we thought. Here’s a thing she did. We’d been looking at photographs with our room-mate and then we went out. When we got back Onyx had gone through the pile and chewed up every one of our room-mate’s photos, causing some pretty hard feelings. Later she would eat all our room-mate’s heirloom Christmas ornaments, handed down through generations. It was pretty much coming down to a decision between Onyx or our room-mate...

Right around this time, our first foster child came to us. We had been thinking of adopting but wanted to make sure we had the capacity to support a child. Foster-kids seemed a less permanent way to see how we felt. Although it wasn’t our intention at the time, this turned out to be the beginning of eleven years of fostering teenagers with disabilities who usually also had a mental health diagnosis, a problematic family history, attachment issues and often an eating disorder.

One of the first things that became clear was that parenting is harder than it looks! Also, that Onyx had a passion, aside from running away and ignoring everything we said... defying us might be her “job,” but her true avocation was caring for children. She thought she was Mary Poppins, or at least Maria from The Sound of Music.

Part of her thinking seemed to be that she wasn’t sure why anyone would trust us with the care of children so she’d better just manage things, so suddenly she was trying to set a good example for kids. As long as they were around. If they went home for the weekend or to a camp, she continued on her demonic course.

We talked a lot about how we’d made a mistake. But by the time we thought of either sending her back to Dr Mike, or sending her to the S.P.C.A. we had our first foster-son, and then our second, and it is interesting to think back on
all the conversations that were, in some sense, projections of what was going on in their lives. Many foster-kids and many people raised “in care” have some variation of an attachment disorder, and most of our kids have had this diagnosis: “. . . attachment disorder is most often used to describe emotional and behavioral problems of young children, but is sometimes applied to school-age children or even to adults. . . . generally the term attachment disorder refers to the absence or distortion of age-appropriate social behaviors with adults. . . . behavior could include a failure to stay near familiar adults in a strange environment or to be comforted by contact with a familiar person” (Wikipedia).

Our kids were mostly hard kids, with long lists of diagnoses, disastrous histories and problematic family contact. I can’t remember how the first conversation got started about how, “We don’t give away family members.” I remember that the child came back saying, “Well how about selling them – do we sell family members?” which surprised us because who would have bought this evil dog, and who would sell a family member? It became what social workers would call a “family signifier” - one of the little things that was a reference point in our odd little family, a private joke that made our family a family: “No matter how bad things get, we won’t give away – or sell – family members.” Later on, with kids with a family history of prostitution this became even more significant. The kids needed to know we were committed; Onyx gave them a way to ask the question they could no longer ask about themselves.

Later, when we adopted our son, at three, one of the diagnoses at the top of a long list was around attachment issues, as is common with toddler or older child adoption. When we watched Lilo and Stitch there is a scene where the orphaned Lilo tells the little monster that, “Ohana means family, family means nobody gets left behind. Or forgotten.” Not even when aliens kidnap you to a prison planet! Not even if you’re a little monster! Leaning up against Onyx, using her as a pillow, he watched the same scene again and again until the videotape needed to be replaced and would ask to hear the story of how nobody gets left behind, or forgotten, when they’re “ohana.”

All our lives went in a new direction as they and she worked on lots of attachment issues together. My partner reminded me this morning of a planning meeting for one of the kids. When asked who should be in the room,
“Who matters to you, that should be there?” he said, “Onyx of course!” and then the meeting happened at our house, instead of in a big impersonal board room, and became a different meeting, with snacks and a tour of his room and an introduction to the dog they loved who could, if asked to “speak,” bark and bark and bark. And then it was time for the meeting and he, too, was able to speak in a way that he’d never been able to previously.

Onyx was a large part of the partnership that’s supported kids and people with disabilities. They all had several good cries into her fur, and her birthday was one of the things they remembered every year (we told them it was Oct 31st in keeping with our opinion of her provenance). They were scandalised when someone called her a mutt, and when we explained that she was not a pure-bred, for a while were working on a petition to the kennel club to ask that the illustrious German Shepherd / Border Collie cross be recognised as a pure-bred breed because, really, everyone would want one.

There was a hard day when one of our kids, who has Autism but was trying desperately to fit into a new school where he believed no one would know he had a disability, came home in tears because another kid, with good intentions, said to him, “So, you’re autistic?” My partner talked to him about being proud of who we are, that each of us has gifts and challenges, and how it didn’t bother Onyx that she was called a mutt, and we took them to get an engraved tag in the shape of a heart with her name and our phone number that read, “beloved mutt.”

I can’t think how many conversations there were about her having been spayed, and what a shame it was that there wouldn’t be more “perfect” German Shepherd / Border Collie cross puppies in the world. Whatever the SPCA might say about planned puppy parenthood, that Onyx would be the last of her kind was a huge loss to civilisation. Many of those conversations led to talks about sex and birth control, and wonderings about her birth family and whether or not they were somewhere searching for her, and how we might track them down and what Onyx’s mother would say when she saw what a perfect dog she had grown into, despite her rough start in life.

Kids with Autism, Down Syndrome, developmental delays, intellectual disabilities, failure to thrive, FAS, FNS, ADD, ADHD, attachment disorder, oppositional defiance, conduct disorder... an endless list of syndromes and acronyms and diagnoses and one treatment: “Let’s take Onyx for a walk and you can hold the leash.” And, later, “Why don’t you take Onyx for a walk
down to the end of the block and we’ll watch to make sure it goes okay and then bring her right back.” And, later, “Yes, it is hard when you think your mom is coming and she doesn’t make it; how would you like to take Onyx for a walk and when you come back we’ll talk.” As their independence grew they’d walk along, and it was a question about which was more proud of the other, dog or child. As Maria sings, in another favourite family movie (who knows how many times Onyx had to sit through it): “With each step I am more certain / Everything will turn out fine / I have confidence the world can be mine / They’ll have to agree I have confidence in me.”

For these kids, to have a creature be entirely pleased and proud of them was often a whole new thing. And for a dog that ran away at the drop of a hat, Onyx always knew to bring back the kids after walking them. Who knows how many secrets she held: “Many a thing you know you’d like tell her / Many a thing she ought to understand / But how do you make her stay? / And listen to all you say / how do you keep a wave upon the sand?”

For us, her “owners,” making her stay was the hard part. She wandered; she walked in the middle of the road like she owned it, when the kids were not around. And, often, we’d say, “We better go get her because if something happens...” Our motivation was the kids and their possible grief, we felt ready to let go of Onyx at any moment. “How long do you think she’s got,” we’d wonder, and sigh.

It is an odd thing to live with a dog you don’t much like. You tolerate her, she tolerates you. We imagine our pets in the best possible way, wailing on our graves when we pass away, “dogging” our footsteps. We had no such illusions about Onyx. She stayed with us because of the foster-kids and then, later, for our son, adopted as a toddler. Onyx looked at us in disbelief when we arrived home with him. “What are you thinking? Who lets these things happen?” and promptly took over, she thought. She followed him around the balcony, keeping him from the edge; he threw her ball over the fence a million times and she still adored him. She sat under his high chair and he decorated her with cheerios. She got half, he got half – and it was a way to get a kid who was frighteningly skinny to eat. When he finally learned to write, hers was one of
the first things he wrote: Daddy, Pop, Onyx. Coming to us with a language delay, he was able to say, “Poppy,” as a too-tiny boy, and she came ever time, wagging her tail, to his delight. And then he graduated to, “On-ee!” before he could wrap his tongue round the x. And then, finally, “ONYX!!! I’m home!” We were all home.

Home was a big thing for these kids. To have someone come when they called, was huge. To have someone who came, every time they called, was a gift that made their eyes shine. They went from fearing, quite reasonably given where they came from, that there would not be enough – not enough food, not enough attention, not enough love – to learning that there was abundance and certainty. At some point each of them crossed a bridge in that it occurred to them that they could give, and it was to Onyx that they gave. They learned to budget their money to buy her gifts, they put off their own dinners to feed her, they thought of things like, “It’s a beautiful day and Onyx might like a walk, so I’ll take her to the park.” She showed them their own growing capacity.

One of the stories in our family mythology is this one, in which walking the dog didn’t go so well. We were booked for photographs for Christmas, and we took Zev and Onyx for a walk before we were to leave. He wanted to hold the leash, and he was dressed so adorably and was so sweet we said yes, it was fine, and he was very proud. “Now don’t let go of the leash, whatever you do,” we cautioned him as we walked through the park. Then someone threw a tennis ball that shot right past her and she was off, and he was down, and sliding through the muddy grass face-first, and then she crossed the gravel path, and he did too, still holding on to the leash, and then she had the ball and stopped and looked back to see him there and brought him the ball. He was sobbing, his face scraped and bloody, tears flooding his cheeks, and they were both looking at us, the parents, thinking, “How could you?” Onyx dropped the ball in his lap and he picked it up, sniffled and threw it for her. She brought it right back and he wrapped his arms around her, crying... Forgiveness.

There is incredible power in having an ally. There is a power in teaching, whether you do it consciously or informally. Something good and God-full comes into one... some Karmic aspect. Onyx taught him to throw a ball, the hardest thing for him, besides writing. Much of the motor coordination he has now came from wanting to please her. His greatest desire was to use a ball thrower in the park, and he managed it. The balls might never have gone quite where he intended, but she was thrilled and so was he. They both dreamed of a day when he’d be able to throw a Frisbee and she could leap into
the air and catch it... they aspired. It will never happen now, but there’s also a power in dreams, met or unmet. Something of God comes into those who aspire and dream.

Still, we wanted a dog for us, one that liked us and wanted to be with us. We researched and decided on a breed, found a breeder, and picked up our puppy when he was finally ready, a little red-haired Irish Terrier. Rufus entered our lives and was obviously uncertain. He didn’t know who we were. We’d sent the kids away for the weekend; we wanted to spend some time alone with our puppy. We were claiming space, claiming the right to have a “good” dog, to make a choice. It was a brave, selfish act to, as parents, get a dog for ourselves. They could have Onyx. Onyx could not believe this – four foster-children, endless kids for respite, an adopted toddler and three kittens later and here she was in her golden years, now a little grey around the muzzle, a little slower on a cold day, and we bring home a puppy? She ignored him. She was having nothing to do with it. Mary Poppins was drawing a line in the sand.

A couple of months later, Rufus somehow got out of the backyard, and while Onyx got away on us all the time, we were used to it, but we *loved* Rufus and he was just a baby and didn’t know anything about traffic. We ran around the back yard looking under bushes and then heard a bark at the front door, and we opened it and found Rufus waiting with Onyx. She’d herded him up the steps and corralled him in front of the door. “What were you thinking? You’re not responsible enough for a puppy!” And she took him on as her protégé and Onyx got pretty much perfect, in the interests of being a good role model. Suddenly she was a great dog, she listened, she attended, she communicated in respectful ways, instead of us always feeling like she was the personification of every negative teacher we’d ever had.

At ten, Onyx began to develop internal infections. It turned out that she had a disease of the bones that had created calcium deposits and growths through her system. Dr Mike said, “It’s surprising she’s still moving around as she does, have you noticed her slowing down and getting stiff?” We really hadn’t. If there was a kid, and a ball, or a stick, or a Frisbee, or a soap bubble, she was there. She didn’t jump quite so high and she let Rufus get the fly balls, but she hadn’t really slowed down. The infections became more troublesome, more difficult to treat, and over the next two years she moved slower and slower.
After a course of medications that didn’t go quite so well as all the rest, she began to fail. On the last appointment to the vet we were sent home with lots of pills and some hope but she laid down in the backyard, only getting up to wag her tail and nuzzle the kids when they got home from school. She went with them for a last slow walk that night. She said goodbye. By the next morning her system was shutting down and the meds, which we’d been so hopeful about, were not working. We told the kids we were uncertain whether she’d make it to Dr Mike’s office. She tried to get up, and couldn’t stand. The kids began to cry. I carried her to the car and he met us there, on his day off, and she passed away in his office.

And all of it is making me think of how some of the most passionate conversations I’ve had with people with disabilities have been about their pets, about the central circle of intimacy in their lives and how these animals of fur, feather and scale are located there with complete certainty. And of Board meetings, meetings with government and teams where there are arguments for and against pets, and the desire to have clearer policies, a more certain and pre-determined course. Who will care for the budgies? They can’t remember to feed their pet – how fair is that? Is it the job of staff to help them with their pets? They can’t afford it. What is our policy?

In the end I wonder if these conversations are our opportunity to test the reality of our person-centredness? This place where so much passion resides, where there is so much projection of fears and such a need for accountability.

It has been my firm belief that all of us have something to give to the world, some spectacular and individual thing that the world is waiting for, and our work is to let that thing blossom and come forth. What we saw with Onyx, a reprobate who became a nanny, and what I now believe might be true is that animals also have a destiny, a thing they move towards and which the world is waiting for, and which we have a role in supporting.