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## What Lula Lacks: Grappling with the Discourse of Autism at Home and in the Field

By Hillary Haldane and David Crawford

### *What Lula Lacks*

Lula arrived six years ago, fourteen months after her brother, an uncomplicated pregnancy and a beautiful birth. Quiet and sweet in the hospital, a good sleeper. A dream child. We got her diagnosis about two and a half years later.

The diagnosis came from a psychiatrist. In a small room with toys she takes notes. Pensively, rhythmically the woman writes. She looks up then takes more notes as Lula climbs around the bookshelves, humming and singing like a whale, fixating on pencils, rocking and roaming, all cheerful obliviousness. We sit anxiously, wanting to direct our daughter, wanting to explain the few tricks we know that make her seem less weird. We are not supposed to. We are here to have the weirdness categorized, and we are supposed to answer the occasional questions the doctor asks and nothing more. We are here for a diagnosis. Finally, with a soft voice, there it is: *autism*. Like a bomb.

We parents are connected at the gut. Both anthropologists, we know what a ‘diagnosis’ is. We know a discourse when confronting one and we know professionally that it’s just a frame, a prismatic shard of culture, a way of talking that is a way of thinking (that is a way of not thinking, too) and the doctor all calm and professional says, ‘I’m sorry’. We gulp down sobs and say, ‘we expected it’. By that time we did know, too, we knew what was coming. We are researchers. We had looked it up. Classic case. Our girl was clearly ‘on the spectrum’. Autism spectrum disorder (ASD). It doesn’t matter if you know, though, because the diagnosis hits beneath the belt, in a place your graduate training cannot protect.

That moment with the doctor, the diagnosis moment, Lula ceased floating free. Her personal dimensions of time and space collapsed and our baby suffused into a spectrum. She became a probability. Professionals would help us locate her in the maelstrom of likelihoods, we were told, they would find the actual in the numerical possibilities. We would have help. But autism ‘means’ little at first because it means anything –anything from totally dysfunctional to different sorts of quirky genius. We were sentenced to Life, but nobody could tell us what that life would be. When you first get it autism is an empty discourse in ominous ways. Then the diagnosis moment passed like a seizure and there she was: Lula still Lula. We took a deep breath and began to develop (or be developed into) a particular understanding of our baby’s manifest oddity. Slowly we came to rely on the discourse.

We came to rely on the discourse of autism for obvious economic reasons, but more ambiguously, more ambivalently, we need it for emotional support. The discourse of autism does things for us. It gets us free schooling, free therapy, and free transportation in one of the best school districts in the United States. Since the age of three, a little yellow bus comes to take Lula to school every day. She gets a special classroom full of extraordinarily competent people who lavish attention on her, strive all day every day to teach her everything from eye contact to how to use a seat belt to reading and jumping on a trampoline. They write reports and send home suggestions and meet with us again and again. We garner opportunities via our diagnosis, dauntingly expensive resources we could never pay for on our own. Our school district is the

envy of other parents of ASD children, and we have staked our future on this district, making professional and personal decisions that allow Lula to stay in these schools. As with most parents of ASD children, the diagnosis has taken over our life, the lives of our whole household, including our son. We are now an autism family, not just a family with autism.

Emotionally, the diagnosis gives us a useful discursive framework, a way of making sense. We can describe why our six year-old doesn't respond when people say 'hello' or ask her age or tell her she's wearing a pretty dress. People ask her a question and wait and begin to look uncomfortable. 'She has autism,' we say, and people look relieved, and reply 'oh,' then pity us. Sometimes they think they make it better by saying, 'I would never have known!' and we retreat into the discourse, defend ourselves with it. The label 'autism' allows us to be economical in our language and evasive in our engagement. We can communicate Lula's entire being with three words: 1. she 2. has 3. autism.

That is an extraordinary thing. Autism is, in the first instance, a *discourse of lack* and it is powerful—Lula *lacks* a set of characteristics typical children have, a set of controls, and that lack defines her, excuses her, excuses us. In our culture we effortlessly express this lack to others (for further exploration of this lack, see Paradiz, 2002). In our middle class, over-educated, parenting-centric society this lack is terrible and helpful. It makes sense. We autism families play by a different set of rules. Other children misbehave at work picnics or soccer games and there is a sort of silent, collective remonstrance of the parents. Our girl misbehaves and people say sympathetically, 'I don't know how they do it.' It's nice, this autism thing. We live in a culture that for the most part blames parents for their children, but autism is a free pass. Or mostly free. People do believe that 'refrigerator mothers' or vaccines or environmental toxins or just 'having bad genes' somehow 'causes' autism, and so we are to blame for that. But even if we are ultimately to blame for the condition, we are not to proximately blame for the behavior—the autism is. Because Lula has autism, she lacks responsibility and so do we. It's liberating.

It is a costly liberation, however. Her lack means that Lula is officially and categorically difficult to handle. Friends will volunteer to babysit Calum, her brother, but not Lula. Family will say, 'I'm comfortable taking Calum to this or that place, but I don't think Lula will want to go'. This is a way of avoiding the admission that they don't want her, don't understand her. Lula is officially special and thus requires a specialist. People can deal with weirdness, but not with a diagnosis of weirdness. Normal adults are responsible for the behavior of normal children in our society, but how could any non-specialist be expected to take responsibility for Lula? Autism gives others a free pass as well, a way to disengage.

However, it is important to emphasize that autism is hardly the worst diagnosis one could have. Other categorized forms of peculiarity have the disadvantages of autism, but not the upsides. Other forms of developmental disability generate the same pity, but are not leavened with hope. Others get fewer resources and even less visibility. Autism at least holds out the possibility of transcendent intelligence, the chance that you might beat the odds and be one of the lucky, competent ones (Murray, 2008). Some advocates espouse a positive valuation of autism, something that rarely happens for, say, cerebral palsy (Bagatell, 2010; Cowen, 2009). Everyone has heard of an uplifting case, and both friends and strangers share these generously. Autistic kids are worth investment, they seem to say. They are not *simple* objects of pity. People tell us hopefully how smart Lula seems 'inside', that we might be surprised by how bright she turns out to be. We won't be surprised. We know she's bright. The problem is not that she's unintelligent; it's that she has autism. Somehow if she is smart enough, then the autism is thought to be irrelevant. In our world, especially our academic world, 'smart' is the currency

most prized by parents, and people hopefully suggest to us that Lula might have a hidden stash. The poor cases with plain, old-fashioned developmental delay, the simply slow: what do they hope for in this world that prizes ‘smart?’ People seem to be saying to us, ‘at *least* Lula has autism,’ like it’s a good thing, and they have ample examples from popular culture to inspire us. ‘I read this book,’ they say, or ‘I saw this thing on TV’. It is all well-meaning, all very sweet, and really quite bizarre. It’s a crazy, painful, useful discourse.

*Where Lack Makes Less Sense (And Disability is Weird Competence)*

In rural Morocco, where both authors sometimes work, or try to work, there is no frame, no discourse, no diagnosis of autism. One of us (David) has spent enough time in one particular village to write an award-winning book about it (Crawford, 2008), but he cannot explain his daughter to his friends there. We can say Lula ‘lacks sense’ or is something like ‘slow,’ but it’s obvious to farmers and shepherds that such phrases are not exactly right. They are not descriptive much less diagnostic. There is no ‘autism’ as such and so Lula-as-diagnosis disappears and all we can do is bring her along and let people look.

Our son Calum struggles, too. In Morocco he struggles with the languages anyway, but it breaks our heart to listen to him earnestly explain (in English) that Lula has ‘autism in her’ and it makes her act strangely. He has to use English. This autism thing, he says, it might make her break things. You have to be careful. He tries to put the discourse to work, and he’s only seven years-old. His efforts were successful in small measure in some contexts, amongst university-educated friends in urban Morocco, for instance, but it didn’t work in the village. As it turned out, it didn’t need to.

We decided to bring our children back to Morocco in summer 2009, for the first time since Lula received her diagnosis. David took Calum for two months, while Hillary and Lula followed for the last five weeks. We assumed the time away from home and school would be too much for Lula. We decided to bring her to the village for only one night, just a quick visit, because we thought it was too dangerous and difficult a place for a daughter who lacked so much.

We arrived on foot in the late afternoon. It was hot and we were thirsty. We’d walked the final seven kilometers after our rental car had resolutely refused to continue up one of the steeper grades of the rutted dirt road. It was June and the majority of the able-bodied villagers were hard at work threshing barley. Only the youngest children were around the house. Our main host popped in to give us warm Cokes and offer tea, but he had to get back to work. Most people were too busy to leave their work, and anyway we wanted to collapse in the shade. This was perfect for the younger children of the house. With the adults occupied at the *inraren*, or threshing areas, the youngsters could examine us.

It did not take long for a small clutch of children to creep into our part of the house, quivering in the shadows of the doorway, suppressing giggles and hoping to be beckoned in. Eventually they lined one wall of our courtyard, looking at us quizzically, not sure of the next move. There were seven of them, ranging in age from two until about nine. At first Lula did not seem to notice the children at all. She was busy drinking her Coke, which she absolutely never gets at home, and staring distractedly into space.

All at once she seemed to notice the kids and said sternly, ‘Miss Lisa’s class, line up. Time to go outside’. The children looked stunned. ‘Miss Lisa’ was Lula’s beloved teacher at her special pre-school. After the announcement she popped up and ran over to the village children,

and then stood at the end of the 'line' she perceived them to be making. Calum ran after her to ensure she wasn't going to do something wrong, wasn't going to push or otherwise hurt one of the younger children. Calum is used to watching out for his sister, and since he had been ruthlessly shepherded by the older village girls when he was previously in the village, he was particularly keen to enforce the safety rules he himself had been made to follow.

But Lula was not up to mischief. She seemed genuinely thrilled at the prospect of playing with the children. She loves school, and she had been asking for some of the friends with whom she attended classes. Now that she had some children to work with, Lula was going to 'make' herself a school. When the 'line' didn't move, didn't behave as it should, she had to reassess. She moved away from the wall, considered the situation, and began inspecting all the children. She went down the row, touched each child, and closely inspected their faces. She sniffed their hair, touched their ragged and unfamiliar clothes, picked at their sores, pulled at their plastic jewelry and hair ribbons. The children wanted to touch Lula, too, and a couple of the older ones reached out and stroked her hair. Calum was going berserk.

The children continued to stand there, transfixed, and Lula continued to scrutinize them until she said brightly, 'Time to sing'. She brought little wooden stools over for the children to sit upon and ushered them into the seats. She began motioning them in her own circle-time songs that she had learned with Miss Lisa. The first song was the straightforward 'Good-bye Lula, good-bye Lula, good-bye Lula, it is time to say good-bye' and Lula proceeded as if the children were fluent in English, and as familiar with the song as she was. Hillary asked all the children their names, and informed Lula that it should be 'good-bye Khadija, Malika, Rashida,' and so forth. The children quickly learned to insert their names as they repeated the English words to the song.

For her part Lula immediately altered the lyrics to reflect her new friends, something we did not know she could do so easily. She had tended to repeatedly insert the names of her absent classmates in all sorts of the scripts that she used, but here she immediately did the 'correct' thing and added the names of the new children.

After singing this song for some time, Lula shifted gears and introduced 'Ring-a-round-the-rosy' with its corresponding movements. Lula seemed unfazed by or unaware of the language barrier, and the fact that the children were not familiar with dancing in the round simply meant that they needed instruction. This she provided. Lula laughed as she grabbed their hands and demonstrated how a proper ring-a-round works. She looked into their eyes as they sang, something she rarely did, and the village children grew increasingly animated and involved in the activity. Everyone caught on quickly and all the children were following Lula's lead and boisterously participated in the song and dance.

Everyone except Calum, who was doing everything possible to disrupt the scene. He is a terrific brother under typical conditions, but this was atypical. He was used to accommodating Lula, translating her. Now she was communicating with the inscrutable mountain children, and Calum could not crack the code. Hillary kept him somewhat at bay, but Calum was certain that Lula would get hurt or hurt somebody and he was wildly jealous of her success at socializing. Lula ignored him and blithely continued to pretend that she was a teacher and the village children were her students. They seemed perfectly thrilled with this arrangement.

It was astonishing. From a parental perspective, this was the first time we had ever seen our girl fully in charge of a situation. It was the first time she had been the center of attention, and one of the first times she was able to reach out and communicate effectively with a group of typical children. Where Calum, the supposedly typical kid, was handicapped by his shyness

stemming from his inability to speak, Lula was perfectly adept at nonverbal communication. Where Calum was confused by the difference in culture, Lula transcended it effortlessly. As she does in her own world, she simply applied the script that seemed most appropriate and in this context it turned out to be a smashing success. It was one of the happiest moments of our parenting lives.

Lula transcended a cultural barrier using her imagination, creativity, and her own unique way of using language—all things the DSM (the Diagnostic and Statistical Manual of Mental Disorders) claims that autistic children lack, all things asserted by a *discourse of lack*. And while we did perceive Lula to lack these things, too, somehow a new context had reframed that lack as competence. Lula did not have to speak Berber, or communicate in a 'normal' manner, because the situation was abnormal. She could play patty-cake and hold hands with village children because she didn't fear the touch of strangers, she hadn't properly internalized the social norms of her home culture and so had no barriers to surmount. Lula didn't notice the local lack (of toys and books, for instance) and they didn't seem to notice hers.

This did not mean that all was well, that we had transcended autism by visiting a village. The squat toilets, for instance, proved to be too 'different' for Lula, and she refused to use them. Eventually she wet herself unabashedly standing in the middle of a room in front of our host. This was embarrassing and we had no way to explain it, no discourse to put to work. David had tried to explain Lula to our host, Abdurrahman, but he had only become irritated that this foreign father would suggest something was 'wrong' with such a normal-appearing daughter. Now Abdurrahman sensed something was wrong, but he and David had no shared discourse to specify it, no way to make it mutually meaningful. We were all left to avoid eye contact, mop up the pee, and change the subject. Lula had a number of other accidents on the trip, too, due to her refusal to use anything but a three-dimensional toilet, and her protests over the restrictions involved in transatlantic travel had us agonizing the whole flight home.

### *Conclusions*

The first point to reiterate is the sheer force of the term 'autism'. It has a power that any parent rightfully fears. You are informed by a professional that your child has autism and instantly the child is transformed. Your whole world is transformed. There is a rich literature about discourses (that is, a discourse about discourse) but one thing often missing is the first person experience of them (see Grandin, 1995, and Prince, 2010, for notable exceptions). Few discourses more starkly reveal how we rely on intellectual understandings to make visceral sense of the world, and in our current era biomedical understandings are paramount. For us, as anthropologists, 'discourse' was an abstract theoretical term, something other people embodied and we critically examined in graduate seminars. Having been consumed by one, we now understand discourse differently. We feel it. We use the discourse to get us things, to excuse ourselves and our daughter, to explain, to make sense, to console, but we cannot claim to control it nearly as much as it controls us.

Next, we wanted to show that the discourse of autism has some revealing peculiarities. At bottom it is a 'discourse of lack,' a way of classifying a lack of expected behaviors and the presence of some unexpected ones. At one level, it is little else. There remains no widely accepted etiology of autism. There is simply a broad set of behaviors (or lack of them) that are parsed and assembled by professionals into a diagnosis. This is meant to explain, but in fact it only labels. Any particular diagnosis selects from an infinity of everyday acts and assigns

significance to some of them, in this case terrifying significance. One of the things autistic people are said to lack is something like culture: that is, the ability to communicate 'naturally' in shared, meaningful ways. This has been critiqued by anthropologists and others (Grinker, 2007; Grinker, 2010), who point out that autism is as much a product of cultural understandings as it is an innate inability to be cultured.

As anthropologists, we understood this. It seems clear that what counts as 'normal' behavior is cultural, that 'diagnosing' is itself a culturally specific behavior, and therefore autism must be cultural. But as parents we never experienced that way. In our everyday lives Lula's classically autistic behavior was a challenge. We found it hard to deal with in every place we have taken her, and we expected anyone would find it challenging in any culture we knew anything about. So, our anthropological understanding of autism as 'merely' or at least deeply cultural is at odds with our parental experience of it as frustratingly immutable, enduring across contexts, and vested in Lula herself.

The incident in the mountains crystallized this tension. Lula had not fundamentally changed, she still had her liabilities. And yet, to the Moroccan children on that day our girl was comprehensible, engaged, wholly human. It would be hard to overstate the exhilaration this produced in us. For a brief time in a dusty village our girl transcended the diagnosis that had dominated her life, that had come to dominate our understanding of her life. On that day, with those kids, Lula did not lack. She was reborn before us, pristine as she had been in those innocent early years: our baby, our girl, unlabeled by medical discourses, beautiful and free.

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