

Autism, Community Building, and Volunteering: A Personal Journey

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1. Introduction

This essay concerns autoethnographic work related to my family and specifically my son, Lenny, who is on the autism spectrum. I will be focusing on a few specific points: first, how autoethnography and one's life experiences can help reflect on social trends in different societies. I will discuss the cases of the US and Japan through my experience. Second, I consider issues related to the autism spectrum, or more specifically, the characteristics of autism in Lenny and personal experiences on this journey with autism. Third, I will discuss community building in the context of crowdfunding, social networks, and how my family have developed a team of volunteers in order to help us.

2. A Criticism of Autoethnography

Autoethnography can be a tricky business—one attempts to explore one's experiences and relate them to broader issues and the community at large in order to describe and critique cultural beliefs, practices, and experiences. While there are potential that autoethnography can provide through using one's life as a source of research, autoethnography is also subject to criticisms of whether the results meet “standard academic” requirements of validity, generalizability, and reliability.

Sara Delamont (2007), in a provocative presentation, is particularly critical of autoethnography, arguing that autoethnography is almost impossible to write and publish ethically, that autoethnography is (personal) experience, and is noticeably lacking in analytic outcome. Finally, she argues that autoethnography focuses on the powerful and not the powerless, which is whom we should be studying as social scientists. She claims that autoethnography violates the two basic tasks of the social sciences, which are (1) to study the social world (introspection, she argues, is not an appropriate substitute for data collection) and (2) to move the discipline forward and change society.

I should state that while I am not the first parent of a child on the spectrum to attempt autoethnography, I am joining Elizabeth Barrett (2017) in her work on

documenting her journey with her son. I do acknowledge that autoethnography (like any approach) has pitfalls, and Delamont infers that simply “looking into oneself” hardly constitutes reasonable grounds for serious academic discourse.

Certainly, there are ethical issues related to autoethnography. In my case, these affect my son and the way in which we have publicized and developed our story in order to build a community. We have a public Facebook page (see *Team Lenny: A Journey with Autism* in references), we ran two crowdfunding campaigns, both my wife, Tomoko, and I give public talks about our story and journey with Lenny, she teaches what she has learned as a parent at a *hoikuen* (day care center) in Chita city, Aichi, and every six months she also teaches people who are training to be teaching assistants to help in public schools with children with special needs (*tokubetsu shienin*) in Nagoya. Our son was three when we first started publicizing our story. We did not seek his consent and he could not give it. On the one hand, we could be accused of “focusing on the powerful”—privileging our desire to seek help for our family through helping us as parents—and not on the “powerless,” our son who cannot speak for himself because he is too young. But on the other hand, in my opinion, the benefits of publicizing our program, seeking volunteers, seeking funds from the community, and building ties within the community by sharing the details of our lives has had a positive effect, certainly for us as a family, but also for others who are looking at the program we are running and learning from it.

I have not sought Lenny’s consent in preparing this paper and he is not in a position to give it. Some may consider this approach to be unethical—the means justifying the ends—but I do not see it that way. I do not necessarily agree with Delamont’s idea that autoethnography violates the two basic tasks of the social sciences in this case. Part of my purpose is to study the social world and the circumstances surrounding our son’s case, and in doing so open up further discussion about the role of family and community regarding disability care.

I also wish to convey, as accurately and evocatively as possible, my experiences as a parent of a child on the autism spectrum. I want to share with my audience feelings and emotions, and hopefully to make an empathic connection. In doing so, my aim is to try and shed some light on views of autism spectrum disorder in Japanese society and to a lesser extent the United States, specifically Hawai‘i.

3. Diagnosis and Despair

At the time of writing Lenny is seven years old. He was born in Nagoya—Tomoko is Japanese, I am Australian. Lenny picked up language very early, both English and Japanese, and was a very responsive child up until the age of thirteen months. He has lost the language he gained a number of times. He demonstrated signs of shared attention, which is where children from around the age of two months engage in joint

attention and conversation-like exchanges with adults during which each is the focus of the other's attention and they take turns exchanging looks, noises and mouth movements. Lenny was able to maintain eye contact with people and laugh with them about a shared object or activity. Several studies have shown that problems with joint attention are associated with developmental processes. Difficulties in establishing joint attention may partially account for differences in social abilities of children with developmental disorders.

Given Lenny's ability to connect with people that I saw, I had dreams that he would become a great communicator. He was, however, often sick and took time to recover from his illnesses. I simply assumed or wanted to believe that this was what happened to all boys. I was wrong.

From the time Lenny was born, Tomoko followed a US-based website called *whattoexpect.com*. Through this she learned that children who are not pointing at objects, who are not giving eye contact, who begin to lose words by the time they are one year old, may have some developmental difficulties. Lenny began to show these traits—he went from being a bright, bubbly child to one who was quite withdrawn. It took us a long time to actually understand the impact of losing joint attention meant. It was extremely confusing; it remains confusing.

Initially I refused to accept that this was actually happening to our son. I finally overcame my denial when I realized he no longer came rushing to the door to greet me when I got home from work and wouldn't even look at me or show any response when I loudly called his name to him a few meters in front of him.

We began to search for solutions online; the prognosis was pretty grim. We began to focus on the word "autism" and then moved into different language – "autism spectrum disorder," "pervasive developmental disorder," in fact, a whole range of new terms that completely confused us.

We consulted specialists in Nagoya, and also Tokyo. The 18-month health checkup set up in our local ward office confirmed our concerns that there were definitely some issues that needed to be addressed in terms of communication. However, the Japanese medical professionals did not offer any solid advice, other than "let's just see how things turn out" (*yōsu mimashō*), which, to parents veering on desperation, is not helpful. An American speech psychologist based in Tokyo we consulted recommended we actually leave Japan permanently because the services here were inadequate.

I recall the words of the author and translator David Mitchell, who wrote the preface to the English edition of Higashida Naoki's bestselling work, *The Reason I Jump*. Higashida was diagnosed with autism when he was five but was able to learn hiragana and katakana and then to write. Mitchell, whose own son is on the autism spectrum wrote that he saw a great gap between what specialists say and what was happening on his kitchen floor. These words continue to hold true for us.

4. The Journey Begins

Although we were not in a position of leaving permanently, we were able to move temporarily to Hawai'i in 2014 when Lenny was 2 years and 8 months old. Before we arrived we contacted Hawai'ian branch of the US Department of Health's Early Childhood Intervention division for information, and we signed up for services upon our arrival. Lenny received a diagnosis of autism spectrum disorder and based on that a team comprised of a speech therapist, and occupational therapist, and a consultant was formed. We were able to get fifteen hours a week of therapy for Lenny, all paid for by the taxes of US citizens, to whom we are very grateful.

We also came in contact with a very active group of parents who advocate on behalf of their children for more government support and services. There are a number of powerful volunteer groups operating non-profit organizations in Hawai'i (and the US in general) who lobby for support.

We discovered a parent-led home-based program called the Son-Rise Program[□] which was founded in the US by the parents of a child who was diagnosed with severe autism in the 1970s when he was a young child. He eventually graduated with a master's degree in biomedical ethics from Brown University and is now teaching the Son-Rise Program himself. This program brought about a fundamental shift in my thinking, attitude and approach to autism, and Lenny's case in particular.

By that stage we had tried a number of approaches including Applied Behavioral Analysis (ABA) and Floortime, which were recommended by different therapists in Hawai'i but did not find these to be effective for Lenny. ABA in particular is promoted and supported with government funding but the approach did not appeal to us at all.

I am not a Son-Rise professional but a parent who uses the program, so my comments come from that perspective. The Son-Rise approach is to use the child's motivation rather than repetition to inspire learning, and we found this to be the most natural fit for us. One lesson I learned is that there are multiple therapies available in dealing with autism spectrum disorder, and none of them will fit every single case or the lifestyle choices of the families, which is probably why there is so much confusion and mystery surrounding autism spectrum disorder. While this can help to explain the "let's-see-how-things-turn-out" message we got initially in Nagoya, it is important that families are exposed to a variety of options, which is what we experienced in Hawai'i.

Although Lenny was eligible for "special needs education" classes in school in Hawai'i, we decided to cut short our time there and return home to Japan to run a Son-Rise program at home full-time, in an environment where we felt comfortable and knew more people.

While I am not going to go into arguments about the different interpretations of autism spectrum disorder, I will explain what it meant for us with Lenny. I have come to view his autism as being defined by challenges he faces with social interaction.

Specifically, there are 4 key elements that the Son-Rise Program® focuses on. This program views autism as a social relational disorder rather than a behavioral disorder. They are:

1. Interactive attention span;
2. Verbal communication;
3. Eye contact and non-verbal communication;
4. flexibility.

In the Son-Rise Program® these are called the four fundamentals of socialization and are divided into 5 stages, stage 1 being the level where the child has the most challenges. When we began the program, Lenny was basically at stage 1. He is now somewhere between stages 3 to 4 for most of them.

Before I discuss community development, I will briefly describe what we do, or rather what we started to do, in order to help with his social relational challenges.

When we first began running our program with Lenny, he had virtually no eye contact. He had some words but was unable to connect his words in ways that we could understand. He had great difficulty with social interaction and we had great difficulty communicating even the simplest requests, such as “put on your shirt.” When we spoke to him, he did not show “normal” signs of comprehension—no nodding, no physical or verbal response.

So how do we encourage social interaction? I will just consider eye contact. Eye contact is one of the crucial elements of communication—to neurotypical people this comes “naturally” but to many people on the spectrum like Lenny, it is a real challenge. In 2014, his eye contact was fleeting at best. In fact, he would actually avoid eye contact. These days, he has great eye contact—in fact, that is no longer a program goal for us.

How did we get to this point? The key in the Son-Rise Program® is to celebrate every moment of eye contact he gives. Through celebrating eye contact, we show him that not only is eye contact a good thing when communicating with others, when he gives us eye contact it shows that he is communicating with us. So, for example, we will start by saying “thanks for looking at me!” Then, when he began to see that we had a positive reaction to that, he started to say words while looking at us. He would look at us and say “ball”—so the celebration point was “thanks for looking at me and for using that word—you are so great!”

Another element of the Son-Rise Program® that I will mention is “joining.” People on the spectrum often engage in repetitive behaviors. It is generally considered that these kinds of behaviors are caused by sensory needs that are not met; in fact, just because someone might engage in these behaviors does not mean they are on the autism spectrum. However, some forms of autism therapy try to redirect and stop the behaviors. We tried redirecting and stopping Lenny’s behaviors, such as when he would roll trains on the floor—they made me feel very uncomfortable because each time he did them, I felt like he was moving further away from the world and going more into his

own. One of his favorite ones when he was during our time in Hawai'i was to repeat phrases from Apple Inc.'s virtual assistant for iOS, Siri, with phrases (English and Japanese versions) like "I'm sorry, I didn't quite get that" or "I don't understand."

The Son-Rise approach does not judge these behaviors in a negative way. As opposed to other approaches, which view repetitive behaviors (often called "stims") as socially inappropriate and requiring redirection or suppression, Son-Rise sees repetitive behaviors (which Son-Rise terms "isms") as ways in which people on the spectrum take care of themselves. Furthermore, it views these behaviors as windows into their world. So we learned that when Lenny engages in repetitive behavior, we participate with deep interest and acceptance without trying to change or redirect the behavior. The purpose of this is to develop a relationship of trust.

At one stage, Lenny was often lying on the floor rolling trains up and down and staring at them. So that is what we did too. If he gave us some eye contact, we celebrated. If he did not show signs of communication, we joined. The first time we had a real breakthrough with Lenny was in Hawai'i. We had received some information about the Son-Rise Program[®] on joining. One day, Lenny was in the bathroom with Tomoko, happily chatting to himself in Siri-speak—"I'm sorry, I didn't get that." Tomoko decided to join him by repeating the phrase. He turned to her and smiled, giving her extended and meaningful eye contact. His action showed her that she accepted what he was doing, and that it was OK. This was a major breakthrough for us because he had not given us such powerful eye contact for so long.

This was the point where our family was in early 2015, which is when Tomoko and I began to think about building a team and creating a community of support for us and Lenny.

5. Building a Team, Creating a Community

Why would I discuss about building a community in this context, which is related to the personal lives of members of my family? In Japan, it has been said that raising a child with "developmental disability" (*hattatsu shōgai*) such as autism spectrum disorder requires parents and a support network of at least 8 adults per child. The reason for building a team was to develop a community of care around Lenny to help him with his communication challenges, but also to help us as parents. But I also want to discuss the dynamics of building community in this context.

Our return to Japan highlighted some significant differences that exist with the United States. Teruyama Junko, in her PhD dissertation entitled "Japan's New Minority: Persons with *Hattatsu Shōgai* (Developmental Disability)" notes that Japanese media describe the special education and legal support systems in the US in relation to *hattatsu shōgai* as being the ideal model to be emulated (16).

I would say that the chief difference I found is that the onus on the US government to

provide services; parents have a right to access services. It surprised us in Hawai'i, for example, that in our initial interview with the coordinator of our services team she wanted to know what we, as parents, wanted for our son. She explained our rights—including the right to accept or reject any suggestions regarding what methods the team used to help Lenny (and us, for that matter). From what we saw, parents played an active role—if they wanted to—in advocating for their children and demanding services, particularly when it came to education.

What happened in Nagoya when we got back? Although Lenny received a diagnosis in Hawai'i we considered getting one here in Japan. The doctor at our local welfare center told us that there was no point in her giving a diagnosis because there were no services available for someone like Lenny. She also noted that Japan was “primitive” (her words) in its approach to developmental disability. In Japan we decided to apply for day care services, which involves placing your son under the care of an organization in a house or facility for a few hours a week. We came across a woman who had two children with special needs and ran one of these facilities. The advice she gave Tomoko was this: go to the local ward office with no makeup on and, if possible, take your child when he is tired or hungry. He may scream and moan—and that's how you will get approval for the services. Sad, but true.

Another fundamental difference between the countries was how parents are involved. There were a range of options available to parents, apart from those provided by the government. There were parent-run NPOs that obtained significant funding to help other parents in Hawai'i, and active engagement to support other parents, particularly those with relatively new diagnoses. We found quite a lot of activity through social media among parents and support groups.

There are three aspects of community development in our case that I will mention. The first is “creating and maintaining a community of volunteers and supporters” who actually work with us in our home-based program with Lenny. This is a process that continually develops as we are now running a full-time home-schooling program for him and we constantly seek support. When we started this in mid-2015, we used Facebook and the Japanese volunteer recruitment site Boramimi, to recruit a team of volunteers, and we put up posters at Nagoya University, which is close to our home.

The second aspect of community development is related to “seeking specific support through the broader community,” which we have done by connecting to the community of musicians in Nagoya and holding a live event, writing about our journey and appearing on a local podcast, and finally, perhaps most significantly as I mentioned, running two crowdfunding campaigns in order to support our program, which is costly. We decided to conduct outreaches, which involve bringing over a senior Son-Rise teacher from the US into our home for intensive short visits and gain insights into how our program with Lenny was going, which is why we ran the public crowdfunding campaigns. One was with the Japanese crowdfunding platform, ReadyFor

(<https://readyfor.jp/projects/teamlenny>); the other was with Generosity (which is no longer online; Generosity is now part of GoFundMe). Seeking support in this way, in my opinion, also serves an educational function as well—presenting our journey in a public manner may help people understand something about autism but it also may support or encourage others going through similar experiences.

The ReadyFor crowdfunding campaign was significant for us because it was the first time we managed to connect to people we did not know through social media. One of the requirements of a ReadyFor campaign was to launch a public Facebook page, which we still have running (although we are not as active as we were in 2016). This was used, in conjunction with our ReadyFor site, to spread our message. It was through ReadyFor that I learned of the range of activities being conducted in Japan by other parents, organizations, businesses, even zoos to raise awareness for their cause through the extensive use of social media.

In addition to raising money to fund our program, another aspect of fundraising activities through social media has been education. One of the outcomes of the ReadyFor campaign we set was to hold a public lecture regarding our program to those who had contributed a certain amount of money. This lecture led to Tomoko being employed by a day care center in the town of Chita in Aichi Prefecture, as mentioned above, to share with some of the staff aspects of her experience with the Son-Rise Program[®], including her insights into the philosophy of the program. I should stress that in this work, and in other public lectures we have given, we make sure to tell the audience that we are not Son-Rise Program[®] professionals but parents who are running the program. The staff of this center have applied the principles to children under their care and have found them to be effective. Tomoko is also involved in lecturing for an NPO to people who are training to become Special Support Education staff (*tokubetsu shien kyōikuin*) at schools, which was an initiative implemented by the Ministry of Education, Culture, Sports etc. in 2007.

When Lenny became of school age in 2018, we began a new phase of our journey. We approached our local school and mentioned the variety of needs he has—dietary concerns, sensory issues, difficulty communicating in groups, amongst others. From our perspective, we feel that it would be easier to homeschool him at this stage, in consultation with the teachers at the school so that we can access textbooks and work with age-appropriate materials. To our surprise (and joy, I might add), the school agreed with this request after we showed them what we have been doing with the Son-Rise Program[®] at home.

What I have presented so far may be questioned or criticized for not meeting the “academic” standards such as validity, generalizability, and reliability. And I fully acknowledge that Delamont’s critique of “lacking in analytic outcome” applies in this case. I have described part of my personal experience. Also, we are a bicultural, bilingual family; we can access funds and information from overseas relatively easily

compared to others. So what kind of contribution can our experience make for families in Japan?

The more we discuss our story, the more I hear of families experiencing severe difficulties just living with day-to-day chores as a result of autism spectrum disorder or other developmental disabilities. I understand this issue intimately, from spending hours and hours trying to understand how to communicate with my son. So not being a “specialist” but rather someone who experiences autism every day has given me some insight into this.

I do not wish to claim that community building is something everyone who is touched with autism will want to aim for. Some people do not want to have their personal struggles on display and they prefer to try and keep them to themselves. They may not want to seek others’ support.

What I would like to suggest, and what I would hope for, is that greater awareness of the kinds of issues that I have presented lead to enhancing and enriching communities of support for people living with someone with autism spectrum disorder.

What I have learned from this journey is the importance of seeing the lessons that Lenny can teach me, both about him and his world, and my responses to that. Although I mentioned “diagnosis and despair,” I can also point to “awareness and hope,” as important factors in my experience. What I once saw as crises in my life can actually become opportunities—and a lot of this depends on my perspectives and attitudes. And, as a parent, I am finding more and more that rather than clinging on to images of how I want my son to act, behave, and communicate, it is far more effective to observe what he is doing, listen to what he is saying, and respond to his cues. Once again, this is not a “one-size-fits-all” approach—these are just the lessons that I take away at this point in my journey.

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