

# Milestones: The Joys and Trials of Autism

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## **Zemi Yenus: Mother, Activist, Pioneer**

“My autistic son is 11 years old.” The newspaper clipping on the wall caught my attention as I sat by the receptionist’s desk at the Joy Center for Autism, waiting to speak with its founder, Zemi Yenus. I had gotten out of my taxi at 8:52 am on that sunny Monday morning and walked on a short dirt road leading to the center. As I took small, hopping steps attempting to avoid the puddles of rainwater that lay stagnant on the ground, I had quietly rehearsed for my first in-person conversation with Zemi, picturing myself eloquently discussing my goals and establishing a good rapport with her. I slightly fidgeted in my seat at the receptionist’s office and took a deep breath, willing my first day to be as good as my imagination has painted it.

Wondering where the receptionist was, I forced my attention to return to the article that was pinned on a board at the very top, leaving the corners of the paper to curl in whenever it was hit by the breeze that often blew into the office. From the center of the clipping, I could make out the details of a gray-scale picture of a slender, middle-aged woman with her arm around a young boy whose features very clearly resembled hers. My curiosity about the article soon overcame the discomfort of being in a new place; I left my seat and walked towards the board. “My autistic son is 11 years old,” the article read. “When he learned how to tie his shoes a few months ago, I was almost as happy as I was the day he was born.”


It was not until a few days into my internship that I met Zemi Yenus. “Zemi could not come in today,” Henok, the lead psychologist at the Joy Center, told me on my first day. I attempted, apparently unsuccessfully, to disguise my disappointment. “She’s pretty busy, but she comes in a few times a week, so you’ll get a chance to work with her,” Henok commented reassuringly as though he had read my thoughts.

Henok wore a gray V-neck sweater on top of a dark blue collared shirt. That was his signature look. His thin-framed, rectangular glasses, once yanked away from his face by a child who was upset about losing his

book bag, gave him the appearance of a professional without compromising the youthfulness of his features. Immediately after our introduction, he started making light conversation about my trip to Addis Ababa and about my course of study at Brandeis, quickly dissipating my anxiety. As Henok led me towards the classrooms on my tour of the compound, I witnessed how his demeanor had the same effect on the children and the staff at the center. He had nicknames for everyone. Terms of endearment that accurately captured aspects of each person’s behavior rolled off his tongue as he poked fun at some of the staff members with playful humor.

During my tour, Henok gave me a brief explanation of autism, one that I imagined he had perfected with many previous tours. “Autism is a developmental disorder that is diagnosed usually within the first 3 years of life, and affects the brain’s development of social and communication skills. Children here mostly experience difficulty in developing language and social interactions and often exhibit repetitive behavior.” After dropping me off in the pre-academic classroom where two special-needs educators worked with twelve students who had started working with shapes, colors, letters and numbers, Henok returned to his desk job.

As I waited to meet Zemi in person, Henok became my point of contact in my attempt



to blend into the structure and practices of the center. On my fourth day at Joy, I was watching the children running around on the playground when a voice from behind called, “Bezaye?” I turned around to face an average-sized woman in her late 50s. She wore a long, dark brown skirt that fell to her ankles and a black cardigan with yellow and orange stripes at the bottom. Her voluminous, dark hair, parted slightly to the left, framed her face and rested on her shoulders. “It is so nice to finally meet you in person,” she spoke as she engulfed me with a hug. Her voice had a distinctive ring to it that was almost majestic; I thought I would recognize it anywhere. Her face, however, was rounder than I remembered and more black spots had found their way to the top of her cheeks. But then again, it had been nearly 10 years since I had seen her beauty school commercial on TV — a lot could change in 10 years.

Zemi was born and raised in Addis Ababa, but she left for Italy during the Red Terror, a time of violent political unrest in the late 1970s. She became employed at a refugee service agency where she worked with immigrants entering the USA. Briefly returning to Ethiopia in 1981, Zemi was accused by the military government of assisting wanted criminals to escape through her work with the refugee services agency. To avoid the threat of being on the government’s blacklist, she emigrated to the United States. In California, where she resided for fourteen years, Zemi completed a course in cosmetology, and eventually established her own beauty salon in Los Angeles.

In 1992, soon after the military regime changed, Zemi returned to Ethiopia for vacation. Dismayed to see so many young girls who had turned to sex work to support themselves and their families, Zemi ultimately decided to move back home and use her skills to give back to her

country. It was with the hope of creating a better alternative for these girls that Zemi established Niana, a pioneer beauty school, which trained over 6000 young men and women in beauty professions along with financial planning and reproductive health ([www.ethioautism.org](http://www.ethioautism.org)).

Meanwhile, at home, Zemi faced the challenges of raising a child with autism. Unable to find schools equipped to work with children with autism spectrum disorder in Ethiopia, Zemi was forced to re-evaluate her decision to return to her home country. “Every morning, I would drive my older son Bilal to school on my way to work; and my younger son Jojo would wave at us through the window as we left. There were times when I would drive out of my house and not be able to stop crying because I felt as though I wasn’t doing anything to help my child,” Zemi spoke quietly when I inquired how the Joy Center came about. She then told me that she began an autism awareness program by including the issue in the beauty services and products exhibitions she organized. During interviews related to her work in Niana, she often talked about autism and her son’s experience with the disorder.

Zemi’s outreach program soon attracted other parents in similar circumstances. Before she recounted the story of a mother she had met years ago, Zemi looked down for a moment as if to gather her thoughts. Alem, Zemi said, was a single mother who made a living by doing housework. Because she had no one to look after her autistic daughter, she would tie her child up in the kitchen as she left for work so that the girl wouldn’t run away or harm herself. “She told me that a part of her died each time she untied her daughter at the end of her work day.” Zemi shook her head and took a deep breath. “And that’s when I realized that advocacy alone was not enough. We needed to take action.”

Born out of a mother’s need to help her child and the children of many others, the Joy Center was established in May 2002 with the mission of empowering children with autism and other related developmental disorders, through educational and therapeutic support that focus on their intellectual, sensory, behavioral, and social development. Beyond this, the center worked to give parents of children with developmental disorders the support that Zemi (along with many other parents) had been lacking.

Zemi’s accomplishments had managed to create an aura of intimidation around her. My anxious anticipation of our first conversation was never because she had been anything less than pleasant to me, but because the extent of her commitment to the Joy Center automatically demanded the same dedication from those who worked for her, including myself. And so, when her gray SUV rolled into the compound, chattering became quieter; hands worked faster and postures stood straighter.

Compliments from Zemi were few and far in between, but when they were given, they carried so much weight. Zemi preferred to lead by example, often asserting that effort, commitment, and mutual support are the keys to success. She ensured that her team members knew what was expected of them individually and what they must achieve as a team. “Setting goals is important,” she would frequently say. “Otherwise, how would you know how far you’ve travelled or how much more you need to go?”

When Zemi interacted with the children at the center, however, her shield of intimidation instantly peeled off. Her eyes lit up with compassion as children gathered around her car and asked her if they could drive it, or when their small fingers curled around her hand as they sang nursery

rhymes with her. Watching her give her son Jojo a tight hug before heading into her office, or laugh hysterically at the selfies he had managed to take on her phone when she was not looking, transformed Zemi from a no-nonsense leader to a caring mother.

## The Joy Center

As the largest project under the Nia Foundation, an indigenous, non-profit organization, the Joy Center for Autism and Other Related Developmental Disorders was the very first institution in Ethiopia to work with children who have developmental disorders. Established because children with developmental disorders had no access to academic and skill training that were tailored to their needs, and parents had no support while navigating life with a special-needs child, Joy incorporates several forms of therapy to enable autistic children to develop cognitive and communication skills and enhance their quality of life within and outside of an academic setting.

The Joy Center is the home of eight programs that work to bring about holistic development in children with autism. The attending program receives newly enrolled children and provides behavioral and basic hygiene training. The occupational therapy program helps children improve their fine motor skills; speech therapy allows them to develop language; and sensory integration therapy conditions them to respond to environmental changes accordingly.

As a transition towards engaging with academic content, the pre-academic class (in which I would be placed) focuses on teaching the children to work in a group setting, sit for extended periods of time, and complete certain tasks upon verbal prompts, while the academic program is geared towards simple math and English

lessons. The children also participated in music and TV programs to engage their imaginations. Each program under the center has a team of three to four special-needs educators.

Much like the other programs, the pre-academic program had a structured and color-coded schedule of activities posted on the wall for the entire week. The classroom was equipped with Legos and puzzles of animal pictures used during cognitive therapy, and alphabet and number sheets used in academic training.

In addition to the teaching staff, three other women work in the kitchen and another two as custodians. The administrative staff consists of Zemi as Managing Director, an Assistant Manager, a Financial Administration Head, a Project Coordinator, two Project Officers, and an Accountant. Except for Henok, who assumed the roles of both psychologist and project officer, the administrative staff had limited daily interactions with the children and with the caregiving staff.


As the first organization to bring the issue of autism to the public's attention in Ethiopia, the Joy Center has managed to start a productive dialogue and create awareness about developmental disorders. Over the course of their time at the center, most children show improvement in behavioral, social, self-help, and communication skills. Since its foundation, the Center has managed to mainstream four children into government-owned schools with which the Center has established partnerships.

One of the Joy Center's biggest achievements, however, is its effort to create a suitable atmosphere that supports the development of the children at home. The Center has been able to create change by supporting not only children with developmental disorders, but also

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parents and guardians who often need sound information on how to help their children. Support groups assist parents with the trials of balancing parenting and work responsibilities, creating a safe and healthy environment for their child, and helping to further their child's progress at home. In addition, by recognizing the fact that a child's disability often also nearly incapacitates parents, especially single ones, Joy has created partnerships with microfinance establishments to allow low-income parents to financially support their families through small business ventures.

On a larger scale, the Joy Center has secured land from the Ethiopian government and has elicited the support of international organizations, such as the Global Fund for Children, UNICEF



and UNESCO, in gathering funds for the construction of a new international-standard treatment center. Upon the completion of this new center, Joy hopes to be able to accommodate the children it currently has on a waiting list due to the lack of space and resources, and begin admitting children outside of Addis Ababa through a boarding program.

### **Culture and Biomedicine: Autism in Ethiopia**

“I have always felt that the action most worth watching is not at the center of things but where edges meet,” Anne Fadiman writes in *The Spirit Catches You and You Fall Down*. “There are interesting frictions and incongruities in these places, and often, if you stand at the point of tangency, you can see both sides better than if you were in the middle of either one” (Fadiman, 120). Fadiman’s book narrates the compelling story of Lia, the Kao family’s daughter, who was diagnosed with epilepsy, and the complex mix of language barrier, cultural beliefs, and lack of compromise that profoundly influenced the trajectory of her treatment.

Lia started experiencing seizures at a very young age. Convinced that the sound of a slammed door caused the onset of her symptoms, Lia’s parents held her older sister responsible. Moreover, they believed that the seizures manifested when Lia was in a trance state in which she communicated with spirits of an invisible world. While the potential for supernatural communication earned her an honored position amongst the Hmong people, it was evident to her family that Lia was suffering. When the Kaos sought medical attention for their daughter, the doctors had no way of learning that Foua and Nao Kao had already diagnosed her problem as a loss of soul, an illness where a spirit catches you and you fall down. Similarly, the Kaos had no knowledge that the doctors recognized

Lia’s condition as epilepsy, a common neurological disorder caused by the misfiring of brain cells (Fadiman, 28). To each group, Lia’s symptoms represented a different illness with a different cause and a different treatment.

The views of biomedicine collided time and time again with those of the Hmong culture. The inability to create a communication between these two systems emerged not only from the apparent language barrier, but also from the lack of awareness and the mistrust in the intentions of the other system. The doctors struggled to get Foua and Nao Kao to comply with Lia’s medication regimen, while the parents feared the social consequences of sacrificing animals to their deity in order to cure their daughter. The medical professionals at the children’s hospital failed to find a way to communicate the concept of side effects and dosage to Lia’s family, while Lia’s parents often missed check-up appointments. This complex set of issues often left the little girl in harm’s way, and unfortunately led to her tragic death.

Reading this book and participating in discussions about it made me realize that medicine is not a discipline that can exist in a vacuum. Rather, in order for it to be fully effective, it needs to be informed by the knowledge and consideration of culture, psychology, and socioeconomic life. The multifaceted relationship between these factors can profoundly influence disease diagnosis, patient treatment, and ultimately, the life and wellness of a human being. As I began my internship at the Joy Center, I wanted to explore how the culture and socioeconomic background of families affected by autism had come to shape the impact of medicine and therapy. I wanted to learn about the efforts, if any, that the organization had made to provide holistic treatment to patients while creating a supportive environment at home.

Autism and autism spectrum disorder (ASD) are both general terms used for a group of complex disorders of brain development. These disorders are characterized, in varying degrees, by difficulties with social interaction, verbal and nonverbal communication, and repetitive behaviors. Following the May 2013 publication of the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders*<sup>1</sup>, distinct subtypes of autism disorders such as childhood disintegrative disorder, pervasive developmental disorder, and Asperger syndrome were merged into one umbrella diagnosis of ASD.

While autism appears to have its roots in very early brain development, its most obvious signs tend to emerge between two and three years of age. Research shows that there is no one cause. Over the last five years, scientists have identified a number of rare genetic changes (mutations) associated with autism. While a small number of these are sufficient to cause autism by themselves, most cases of autism likely appear as a result of the combination of autism risk genes and environmental factors that influence early brain development. Advanced parental age at time of conception, maternal illness during pregnancy, and birthing difficulties — particularly those involving oxygen deprivation to the baby’s brain — have been found to increase the incidence and severity of autism in children who already have susceptible genes.

Despite the fact that autism appears in one out of 68 children with varying degrees of severity, autism awareness in Ethiopia is very minimal. Due to the nature of their symptoms, autism and other related neurological disorders are largely attributed to supernatural causes in several regions of Ethiopia. Many children with autism have very limited capacity for language, which often only leaves them

with gestures and undecipherable sounds to express themselves. When unable to be understood by others, children often get frustrated and harm themselves or the person next to them, usually by biting or scratching.<sup>2</sup> Most children on the spectrum are hypersensitive to certain sensory stimuli and are therefore more affected by sudden motion, loud noise, or the touch of a soft object than other children would be. An overload of such stimuli can cause these children to separate themselves from a crowd, plug their ears with their fingers and rock back on forth, or produce a sound repeatedly in an effort to ease their sensory chaos.

The lack of an alternative explanation, coupled with the high percentage of Ethiopia's population affiliated with some religious sect, mean that most Ethiopians view these symptoms of autism as a curse from a supreme being, rather than as a medical condition with a yet-to-be-identified cause. This association of autism with supernatural causes unfortunately ties the disorder to immorality<sup>3</sup>, leading it to be perceived as the result of the immoral actions of parents. This not only causes parents to feel ashamed to speak about their children's disorder or hold themselves personally responsible for its occurrence, but also leads to the unfortunate disenfranchisement of children with the disorder.

This stigma associated with autism is not only evident in people's individual interactions with the children, but is also reflected in the scarcity of facilities that take care of children with disabilities and of services that provide support for parents with such children. The perception of autism in Ethiopia is a clear example of how culture and socioeconomic backgrounds can profoundly affect the availability of health care services. The taboo associated with the disorder has

effectively removed it from discussions in the public health sphere and has resulted in very little awareness, which becomes evident in its frequent misdiagnosis as a psychiatric condition (Ametepee et al, 12). Unfortunately, many professionals in the medical, educational, and vocational training fields are still unaware of how such disorders affect people and how to successfully work with autistic individuals. These factors, along with the scarcity of facilities that specialize in autism, have left many children unable to receive treatment. As a result, children with autism and related disorders do not have access to academic, social, and communicational skills trainings, and therefore do not get involved in the overall socioeconomic activities of the community.

According to Fadiman, the kinds of language that we use to describe something say far more about us, and our attachment to our own frame of reference, than they do about what we are describing. As such, in Ethiopia as elsewhere, the language that frames the discussion of autism has often perpetuated the stigma that was engrained in people's attitudes. The Joy Center has focused on reconstructing the language used to discuss autism, in order to remove the moral stigma that excluded children from several facilities and services.

For instance, Joy attempts to break the association that is established between health and autism by using the terms "autistic" and "non-autistic" to distinguish between children who manifest symptoms and those who don't, as opposed to "autistic" and "healthy." The presence of the disorder does not mean that the child is any less healthy in other ways, or has any fewer of the other needs that children have. Furthermore, Joy attempts to disentangle autism from the concept of stagnancy. With many cognitive disabilities, the perception of the lack of

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progress closes many off from treatment and intervention options. Disabled children are then further silenced and excluded from society when not given the chance to become a part of a community, to harness social relationships, and to partake in activities other children have the opportunity to participate in. By using slogans such as "Listen to us. Understand us. Include us," Joy reflects the importance of a paradigm shift in public opinion in order to make real strides in the movement for autism awareness.

Moreover, the name of the center, Joy, was a derivative of Zemi's son's name, Jojo, but also reflects the literal definition of the world: that this was a place that was where

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children with autism could feel at home and experience the joy of having their needs understood and accommodated. The slogan of the center, written with a bright yellow paint on the front door of its compound, is “A special place for special kids,” reflecting the belief that having special needs does not have to require exclusion, but should rather warrant the creation of space that works with those needs.

Much focus in Joy’s work has been placed on programs raising awareness in order to create public spaces that are friendlier to children with autism, to have health care providers who are more knowledgeable, and to help parents be better equipped to assist their children. By decreasing the taboo about discussing developmental disorders, the Center enables more parents to receive help for their children and emotional support for themselves. Creating a distinction between moral condemnation and a physical disorder that happens to manifest itself behaviorally, Joy continues to create public forums that further the public’s knowledge of their various projects.

Similar to Lia’s case, we encountered compliance issues in maintaining consistency of expectations between center and home. In addition to cognitive and motor skills trainings, the children at Joy receive extensive behavioral training to increase their social skills, to encourage them to listen to instructions, and to help them recognize verbal and non-verbal cues on how to interact with others. A couple of weeks into my internship, I learned that many children would follow guidance and behave well at the Center, but challenge their parents at home. Families often failed to maintain the disciplinary methods that were used at the Center or to follow all of the dietary restrictions that were in place to moderate the children’s moods.

Psychiatrist and medical anthropologist Arthur Kleinman says, “...‘compliance’ is a lousy term. It implies moral hegemony... Instead of looking at a model of coercion, look at a model of mediation” (Kleinman, 261). In this vein, it became clear that getting parents to further the center’s efforts succeeded only when a compromise could be achieved.

For example, Abdu’s mother frequently sent her son to school with sugary snacks (or after having eaten them at home)

despite the fact that the teachers had informed her repeatedly that such a diet made him hyperactive and unable to concentrate in the classroom. He would have a snack before coming to school and remain restless and fidgety for hours. Because his constant activity distracted the other children, Askal, one of the teachers I worked with, would sometimes instruct me to take him out of the classroom and sit with him in one of the isolated therapy rooms. In spite of the efforts the teachers made to communicate this to Abdu’s mother, she failed to say “no” to her son, because she just “could not deny him what he wanted.” In her mind, giving him the snacks he requested was the way she made up for all the other things she was unable to do for him. It was only when the teachers understood this that they were able to more effectively sit with her and recommend snacks with lower sugar content. The recognition of the mother’s need to take care of her child by not denying him what he wanted led the teachers to attempt a method of compromise in which the mother still gets the emotional fulfillment of honoring her child’s request without significantly affecting his productivity at school.

Perhaps the most significant integration between treatment and culture that I observed at Joy was the Abugida phonetic language the center created to teach its students how to read. This language allowed for the rearrangement of English words to use a similar phonetic system as Amharic, the most widely spoken language in Ethiopia. Since the Amharic language has symbol for every sound, all words are pronounced exactly as they are written. Although it took some getting used to, writing “one” as “wan” or “ball” as “bol”, this phonetic approach made it easier for the children (who thrived on consistency) to absorb information. Paying attention to the patient or student experience reveals factors that can influence treatment and

learning but would otherwise be left unnoticed. By noticing that children with autism had an easier time assimilating information into their pre-existing frameworks, and accommodating those frameworks instead of having to create new ones, the Center used a system that allowed the kids to use the language that they already knew to learn new information.

Throughout my internship, I noticed how the very intricate interaction between culture, health care, and education makes it difficult to influence one without affecting the others. It became evident to me that centering oneself in culture or in the purely biomedical processes results in information being lost, often leading to miscommunication that harms both sides. Finding a place at the tangent where these two factors meet, however, makes for a holistic treatment that leads to rewarding outcomes.

## The Orange Swings

“Do you mind taking him to the swings?” Blen asked me as she moved the table by the classroom door to let Aron, a 6-year-old boy, out of his seat. He had been crying uncontrollably since his mother dropped him off that morning. Getting him water or taking him to the bathroom had not made the slightest difference. Blen, the teacher I was assisting, looked at me encouragingly, extending the little boy’s arm towards me. “The swings usually calm him down,” she explained. I was stunned to be entrusted with the responsibility of independently caring for a child on only my second day at the Center. I reluctantly took the boy’s arm and walked with him out of the pre-academic classroom. “I’ll be up there in just a minute,” she reassuringly called after me.

We passed the kitchen and the speech therapy classroom to face a small incline that led to the playground. The boy’s voice was now breaking as he attempted to take

short, shallow breaths. I let go of his hand and slowly placed my hand on his back; he did not recoil from my touch. “Shh,” I whispered, rubbing his back gently and hoping that he would soon start feeling better.


At the top of the concrete-floored incline were the administrative offices, situated in what must have previously been a domestic residence. To the left of the main building was an obstacle course consisting of ladders, small hills, and a slide. My eyes quickly scanned the large, forest-green gate and the tall trees that provided a generous shade to the playground. The top half of the wall closest to me was covered with a sign on which green paint casually lettered the same slogan as the one on the compound’s main gate: “A Special Place for Special Kids.” The shaded seating area in front of the wall had a plastic table and a few chairs where Blen and the other teachers liked to sip their morning tea and talk about the amusing things their students have done. A bit farther from there was the pair of swings.

Hanging from blue and red posts, the swings were painted a bright orange color that reminded me of a beautiful sunrise. The alternating rain and sun of the season were not so kind to the paint on the back of the swings, leaving small patches of grey metal exposed. I guided Aron towards the swings with my arm still on his back. “You’ll sit here and I’ll push you very slowly, okay?” I spoke to the boy. He sat down with his small fingers tightly coiled around the chains of the swing. “Good job!” I encouraged him. Anticipating his reaction, I pushed the swing, each time with slightly more force than before. Suddenly, the little boy stopped crying and started contracting and relaxing his back to make the swings move more. As I remember this moment, I often think about how the simple back and forth movement of the swing brought comfort not only to the little boy, but to

me as well. With every cycle, he dared to swing a little bit farther and I dared to push a little bit harder. And although the swing was simply oscillating in place, the excitement on Aron’s face as it went up or the way he twinkled his fingers as it came down made that moment so rewarding.

Ever since my first day, those swings became my domain. I would sit on the horizontal bars when I arrived early in the morning or stay in the shade next to them during playtime and as the children were heading home. The swings were just as popular with the children as they were with me, and that gave me multiple opportunities to bond with the children, to identify what upset them and what made them happy, and to establish a rapport that allowed them to feel safe around me. I taught Aron, who at the time had been at the center for only three months and was just starting to use verbal language, how to say “*gefign*” (push me); I persuaded another student to wait in line until the other children were done playing. I was even rendered speechless by the ability of a five-year-old to comprehend the idea of negotiation when he offered to give me a hug before asking me to push him on the swings.

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Despite my almost daily attempts, Aron never learned my name. He always called me “Blen”; he called every female-bodied person at the center “Blen.” I soon found out that every male was “Endale.” He would run into the compound when his parents dropped him off in the morning and look for me, Askal or Blen. Once he found one of us, he would throw his backpack to us and run to the swings. The only thing that ever kept him away from the swings was Sheba, the compound dog, which he was both terrified of and fascinated with. When he saw her, he would come and plead with me in the few words he could put together to get rid of her, and hide behind my back with his arms tightly wrapped around my waist. When Sheba was not looking, his fascination would manage to trump his fear and he would extend a shaky hand to pet her. He would then turn around and look at me with the largest grin on his face, his fingers twinkling like they always did when he got excited.

Aron was always the source of laughter in the pre-academic classroom. He was far more hyperactive than any other student we had, which meant that we spent a lot of time attempting to find activities that calmed him down and allowed him to focus rather than covering academic materials. He enjoyed putting Lego pieces together and loved taking them apart even more. If a phone were left out, he would grab it, and cry when someone asked him to give it back. But more than anything else, he loved dancing. He would return from lunch, turn on the TV and yell “eskis” (a shorter term for “eskista,” a famous Ethiopian dance) until someone played some music for him.

Observing Aron and so many of the other children at the Center gave me valuable insight into how autism manifests itself. Each kid had his or her own set of behaviors that made him or her distinctive. Aron didn’t like to sit for a long time;

Lani rarely spoke at school, but recited everything that happened to her parents at home; Aman called the number twenty “twenty-zero” because he was a stickler for patterns; and Zena loved getting her hair done so much that she would tie and untie it multiple times a day.

Despite the wonderful interactions I was having with the children at Joy, I sometimes found myself wondering if my presence was having any significant impact. With the notion of linear progress haunting my perceptions and assessments, I found it difficult to deal with the regressions that happened every now and then. Words that were read correctly on Friday might be forgotten by Monday; children who were potty trained would urinate on themselves; or a child who was taught to not harm others would scratch a volunteer. “It happens with all of us,” Henok reassured me. “Sometimes you have to spend a lot of time to see a tangible change. But the process teaches you a lot and the children get the love and attention that they need.”

Henok was right. During my time at Joy, I assumed responsibilities ranging from administering therapies and academic lessons to organizing the peer outreach program under the organization’s fundraising campaign. Yet hearing Dani count to 100 for the first time, or watching Elda learn to move to the rhythm of a new song, or having Sehen point me out to her brother as “the teacher from my class,” were possibly the most fulfilling moments of this job. And just like the swings, there was much gained in the back and forth.

### **“It Concerns Me”: Social Change Through Activism**

Wednesdays at Joy Center were shopping days. After morning line-up, the teachers took the children out to a local mini-market to buy fruits or bread or, once every few

weeks, to drink some fresh mango juice. Blen and Askal would always hold the hands of the more active children, the ones who loved to run around, for fear that because of my lack of experience, I might not be able to keep them with me. Holding onto the remaining children, I followed them as they made multiple turns through the cobble-stoned neighborhood to avoid the main street. As we walked, I often asked my nine-year-old student Lani to sing me her favorite song, “*Etemete*”, or my other student Dani to name the colors on his clothing.

Upon returning from my first trip, I curiously asked Zemi what the purpose of these trips was. “We want to help our children learn how to interact with the community outside of Joy.” She then explained how parents with children on the autism spectrum often face challenges while navigating public spaces, because they are afraid of having their children be perceived as spoiled, and themselves as unfit parents. “By training the children here, we hope to make parents feel more comfortable to spend time with their children outside of their homes,” Zemi added.

After my conversation with Zemi, our Wednesday trips became valuable opportunities for me to observe not only the behavior of the children in an unfamiliar environment, but also the reaction of the community to their presence. As we made our way through the quiet domestic residences, people from the neighborhood smiled and acknowledged us. Others who happened to walk the same path as us often followed us with their curious eyes. It was, however, when a child cried for a second round of juice or attempted to run out of the shop or even tried to communicate non-verbally, that reality sunk in for most of our observers and discomfort took over. And if discomfort was missing, absolute pity was in its place.



The lack of awareness about autism means that most parents do not have any information about the disorder until it appears in their own family. In fact, this had been the case with Zemi. Jojo was 4 years old when his father was watching a television program on autism and realized that his son had many of the symptoms associated with the disorder. Because of their economic privilege, Zemi and her husband were able to take their son to England where he was officially diagnosed, and they received professional help that better equipped them to assist their son. It was upon their return that Zemi started programs raising awareness about autism, only to realize so many other families, most of whom were from lower socioeconomic backgrounds, remained helpless.

Joy has created and continues to create public forums where autism is discussed and destigmatized. Every April, during World Autism Awareness Day, Joy organizes a march throughout the city of Addis Ababa. The staff and students along with hundreds of people from the general public participate in this march by wearing the center's caps and t-shirts and holding signs with slogans. Joy also takes part in the biannual citywide exhibition, where it not only promotes itself and its work to the public, but also finds sponsors that can either financially or materially support the organization's ongoing projects. With the launching of its new fundraising campaign, "A Day's Income for Joy," the Center hopes to use its partner organizations, parents, and student volunteers to reach a wider public with an invitation to contribute one day's income to the construction fund of the new center.

Since its establishment in 2002, Joy has operated with the belief that social change begins at an individual level. It is only when people, especially parents of children with autism, are able to voice

their concerns about the social injustices of developmental disorders that they can inspire others to become advocates and informed citizens who will then contribute to change. "And change has so many faces, you know," Zemi once said to me. "You can offer to watch your neighbors' autistic child when they're not around; you can fundraise; you can volunteer at organizations like Joy; you can lobby for more inclusive healthcare policies...and with each of these, it is your concern that is bringing tangible change."

This idea of change has held true in Joy's journey over the past 13 years. It was the concern for the lack of accommodation and resources for children with autism that birthed the center. It was investment in the continued development of the children at the center that led to the establishment of side projects that helped parents gain emotional and financial support. And it is the continued need to secure the wellbeing of children with autism that will continue to break the silence that has always surrounded the subject, and bring about education and health care policies that are more inclusive of special populations.

### **Small Changes**

"I've always wanted to have a son," she said in a tone that was barely audible. "When I thought of myself as a mother, I've always imagined having a son. I don't know...maybe I wanted it too much." She forced her lips to part into a smile as her eyes fought to hold back the tears that glazed over them. My aunt had just returned from a trip to the hospital where the pediatrician had told her that her son was autistic. She got up abruptly, said she wanted to be alone and locked herself in her bedroom. Moments later, we could hear her sobbing uncontrollably from the other side.

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Over the years, I have watched my aunt take her son to many medical appointments, search all over the city of Addis Ababa for pharmacies that carry the medication he needs, and stay up for hours to get him to go to bed. All the while, she has grappled with the idea of not being a good-enough mother for her autistic child or even for her older daughter, who was not getting enough attention.

"My autistic son is 11 years old," I had read in the creased article pinned to the board on my very first day at Joy. "When he learned how to tie his shoes a few months ago, I was almost as happy as I was the day he was born." I imagined the smile that colored her face, lifted her cheeks, and wrinkled the skin around her eyes. It was the same smile that colored my aunt's face when her son called her "mama" for the first time at age four. It was the same smile that lifted her cheeks when her son finally returned her hug.

In that moment when I still had little idea of all that was awaiting me, I read the final quote of the article and understood: "There are so many milestones. And the smallest successes are the most joyous."

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## Notes

1. The Diagnostic and Statistical Manual of Mental Disorders (DSM), published by the American Psychiatric Association (APA), is a guideline that offers standard criteria for the classification of mental disorders. It is used by clinicians, researchers, psychiatric drug regulation agencies, health insurance companies, pharmaceuticals, and policy makers. The DSM, now in its fifth edition, is the primary tool used for the diagnosis of autism. For more information on autism diagnosis, go to <https://www.autismspeaks.org/what-autism/diagnosis/dsm-5-diagnostic-criteria>.

2. Ametepee et al argue that the symptoms of autism can vary from place to place. The study has revealed that children with autism in Africa on average tend to display less aggressive behavior than those in the US. The reason for this difference remains unidentified.

3. "Just world fallacy" is the concept that refers to our faulty perception of living in a just world. This perception, reinforced by childhood tales, allows us to have explanation for event that would otherwise not make sense. This, however, often means that we perceive people in undesirable situation to be the causes of their circumstances. While this concept can apply widely across several phenomena, it is also the reason why we perceive disabilities as having a moral component: those who live with disabilities must have committed immoral acts to be the way they are.