Disturbing the Silence: Social Justice in Special Needs Education

"I've always wanted to have a son... 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 said, forcing 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.

To bring a human being to this planet and to be responsible for a life is a task of unprecedented weight. Yet, to raise a child with special needs is an even greater challenge that takes a social, financial and emotional toll on unsuspecting parents, especially those in developing nations like Ethiopia. The severe lack of awareness of such issues makes the day-to-day lives of parents even more challenging. Over the years, I have watched my aunt take her child to regular check ups, 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 grappled with the idea of not being a good enough mother for her autistic child or even her older daughter, who was not getting enough attention. It broke my heart that there were not many accessible facilities or specialized
healthcare systems to help my aunt raise her child or my cousin to get the support he needs.

As an international student, a significant part of why I came to the US is to study Neuroscience, a field that is not available in Ethiopia, and contribute to the very restricted research field and healthcare service in my country. To this end, while pursuing a pre-med track at here at Brandeis, I never understood why I was required to take a variety of classes from fields that I believed had little or no connection to the science of living things. Nonetheless, during spring semester of my first year, I took an Anthropology class entitled *Introduction to the Comparative Studies of Human Societies* to fulfill my Social Science and Non-Western class requirements. The class discussed a variety of subjects ranging from food, to body image, to racism and colonization. Towards the end of the semester, the class read *The Spirit Catches You and You Fall Down*, a medical anthropology book that chronicles the struggles of a Hmong refugee family from Laos and their interactions with the health care system in California. The book tells the tragic story of how the family’s daughter was diagnosed with epilepsy and how cultural conflict, language barrier and parental lack of awareness ultimately led to her 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 complex relationship between these factors can profoundly influences disease diagnosis, patient treatment and ultimately, the life and wellness of a human being. This understanding encouraged me to pursue the social and cultural aspects of medicine and healthcare by minoring in Anthropology.
My interest in health care and anthropology soon fused with the principle of social justice that I encountered at Brandeis and opened my eyes to the many ways that we, as a society, both knowingly and unknowingly, discriminate against people with disabilities, disorders and limitations of any kind. This discrimination is not only evident in our individual interactions with them, but is also reflected in the lack of facilities to take care of children with disabilities and in the unavailability of services that provide support for the parents of such children. It was upon this realization that I decided to establish a project in Ethiopia to help children with special needs, particularly those with autism spectrum disorder.

Autism is a developmental disorder that appears in the first 3 years of life, and affects the brain's normal development of social and communication skills. As such, children with Autism experience difficulty in learning language, comprehending and responding to other people. Unfortunately, many professionals in the medical, educational and vocational training fields are still unaware of how autism affects people and how to successfully work with autistic individuals. As a result, children with autism and related disorders do not have access to academic, social, communicational skills trainings and therefore, do not get involved in the overall socioeconomic activities in the community.

Considering these conditions, I want to establish a project that is primarily focuses on raising awareness about autism and removing the stigma associated with it. Although I ultimately want to see my project grow into a sustainable non-governmental organization, for the upcoming summer, it is more productive to work in partnership with an already established organization. Hence, I have selected the Nia Foundations, a non-profit
organization that strives to empower and inspire individuals with developmental disorders through education, rehabilitation, vocational training, and leadership development. In partnership with this organization, I hope to recruit high school and college students to organize and participate in a citywide march. To further this effort, I am also discussing the establishment of an Autism Awareness Club in my former high school with the current principal.

During my internship, I will be participating in speech therapy and social skills trainings, taking part in workshops designed to equip parents with the techniques to enhance their children’s communication and social interaction abilities and working with professionals in special needs education to plan activities for the children at the center. I would also love to use this internship to gain a better understanding of how non-profit organizations are established, how they gather funds to facilitate their projects and how they identify the areas of need for their target population. I expect that familiarizing myself with such processes will be instrumental in establishing my own project and making it sustainable.

In preparation for my intended internship, I plan to take NBIO 146A: The Neurobiology of Human Diseases. This class is a lecture and literature-based overview of the neurological and psychiatric disorders including autism, mental retardation, schizophrenia, and other developmental and degenerative disorders. I expect that the class will help me learn and understand more about autism and allow me to get more out of my prospective internship.

There is no question that every child deserves to be loved, cherished and protected; and a developmental disorder should be no reason to lose any of those rights. It is
important that our educational system becomes more accommodating to people with disabilities and that our social gates are open to all people. It is essential that parents with special needs children receive the support that they need, that autism is not a taboo and that getting access to medication and health care is not an uphill battle. Hence, I would truly be honored to use my summer to bring social justice to the field of special needs education and care in Ethiopia.