Faith, Sofiya, Alex, and Breanna

Group Memo - Eden Autism ProCES

ANT 240

May 12, 2020

<p style="text-align:center">Challenging Stereotypes Through the Empirical Lantern</p>

What is normal vs abnormal and who gets to decide that? This question is especially relevant in the discussion of autism and the need for "special" treatment for individuals with autism. The existence of specialized treatment and services for people with autism should not imply that these people are deficient because they are not neurotypical but should only indicate that they are different from the "normal." By addressing the stereotypes about autism, we came to appreciate the fact that individuals with autism are sometimes faced with discrimination because people can assume that those with autism are deficient in some way, be it emotional, intellectual, or social abilities. Working with the community partner Eden Autism led to important insights about the power of scientific authority in determining what is considered normal and abnormal. We also saw how stereotypes and myths can arise from outdated information about autism. We appreciated the power of the empirical lantern to challenge these stereotypes upon analyzing Farmer's work about structural violence, Hacking's theory of "making up people," and Byron's description of the medical practice of constructing the idea of a body and a disease to make up a mold of a stereotypical patient. Synthesizing these sources and looking at the stereotypes surrounding autism through the lens of medical anthropology generated interesting insights about the role of society and the medical field in the construction of a person with autism as an object of diagnosis and treatment.

We discussed Farmer's insightful perspectives into structural violence and the role of the environment on the individual. According to Farmer, "one must embed individual biography in the larger matrix of culture, history and political economy" to understand hardship (Farmer, 41). Melinda Gorny McAleer, who is the Chief Development Officer at Eden Autism, explained in the interview that less than half a century ago autism was considered a rare diagnosis, and its development was incorrectly blamed on bad parenting style. This attitude towards autism was prevalent in society, which played a significant role in inadequate screening for autism and the desire of parents to prevent their child from receiving the label. Unfortunately, this meant that many children with autism were not diagnosed and did not receive help through early intervention programs like those offered by Eden Autism because of the cultural context, particularly the stigma surrounding autism. This situation serves as yet another example of the importance of the cultural context of hardship as described by Farmer.

The impact of the cultural environment in the medical approach to autism goes even deeper than influencing the readiness of parents to screen their child for autism and the availability of treatment options. The perception of autism by the society and the medical community as well as the official diagnostic criteria have a deciding role in whether a person is identified with the label of autism. Diagnosing someone with autism is a form of "making up people" as described by Hacking in his theoretical work. "Making up people" is the process of shaping a person's story and sometimes even identity by the ideas and stereotypes that are projected on the person by society. This abstract idea finds practical application when discussing autism as a neurodevelopmental disorder that has been officially recognized for the first time as recently as the past century. In fact, medical professionals have also recognized the presence of

making up people in the medical field. Byron Good in his book *Medicine, Rationality, and the Human Experience* called attention to the common practice in medicine of *constructing* the human body and *formulating* illness in the process of diagnosing a disease and performing therapeutic activities (65). The construction of the body and the illness is a form of making up people. Doctors are taught to deconstruct the illness narrative told by the patient and to reconstruct it in a very specific way to fit the mold of the stereotypical patient.

The practice of making up people in medical practice as it applies to autism is not immediately obvious. However, close reading of the materials about autism and specifically the stereotypes that surround people with autism revealed that the idea of autism has been heavily impacted by the practice of making up people described by Hacking and constructing disease as explained by Good. Particularly, the scientific community now recognizes that many of the facts previously believed about people with autism are not supported by evidence. In fact, some of the stereotypes surrounding people with autism were the byproducts of the medical community constructing the criteria for diagnosing the disorder in efforts to make them consistent with their limited understanding of autism. For example, one of the most common stereotypes is that people with autism are incapable of feeling empathy because it has been observed that their outward reactions to certain emotional situations are less animated and engaged than the outward reactions of neurotypical people. This seeming lack of ability to experience empathy was considered a hallmark symptom of autism by medical professionals and researchers for many years (Hadjikhani, 2014). However, brain activation studies have shown that individuals with ASD have brain activation similar to that of neurotypical individuals in response to observing someone's suffering. In fact, people with ASD were hypersensitive to the distressing stimuli as

shown by their brain activation. The researchers now believe that the seemingly emotionless reactions stem not from the inability to empathize but rather from not knowing how to express their empathy (Hadjikhani, 2014). This vivid example shows the shortcomings of relying on inadequate evidence to construct the diagnostic criteria for a condition like autism.

In addition, according to Autism Speaks, the prevalence of autism has increased by 600% in the last 20 years. This increase can in part be attributed to expanded diagnostic criteria and financial and care incentives to diagnose children. Scientific American states that in 2013, the current Diagnostic and Statistical Manual of Mental Disorders "collapsed autism, Asperger syndrome and pervasive developmental disorder-not otherwise specified into a single diagnosis." This illustrates clearly the ability of terms and definitions to "make up" people, as well as in this case to change people into something they were not before. A child diagnosed with Asperger syndrome overnight became someone else to the world and the medical field. This change could have also affected either positively or negatively the resources available to this child and their family. Using the empirical lantern is especially needed when such changes are implemented to avoid the unintended consequences of making up people and artificially constructing the idea of a person as an object of diagnosis and treatment.

The application of the theory of making up people and constructing disease in no way suggests that autism itself is a "made-up" disease, but it does warrant careful contemplation before applying the umbrella term and all of its connotations to an individual, especially given the fact that autism covers a whole spectrum of deviations. This is exactly why treatment facilities and residential services for people with autism have to emphasize an individualistic

approach to every person to avoid imposing characteristics or symptoms that are dictated by the official definition of autism but do not necessarily apply to the individual.

The empirical lantern is a necessary tool to achieve a more holistic understanding of autism and develop a meaningful individualized approach to a person with autism. It is clear that Eden Autism employs this invaluable anthropological strategy when working with people with autism as well as their families as evidenced by their intimate understanding of the unique challenges facing these people. For example, Melinda told us about some of the unique hardships faced by parents of children with autism and how Eden Autism strives to provide them with resources to cope with these difficulties. Some parents find themselves isolated from their families and friends. Family members become uncomfortable with the peculiar behavior of the children with autism during family gatherings. Parents feel trapped in their houses, finding it difficult to find a suitable babysitter to watch after their child to allow them to visit friends. These unique experiences of parents play an important role in understanding autism as an illness experience that heavily involves not only the individual with autism but also the parents and the community. Eden Autism becomes a crucial resource for parents which provides support through educational and treatment services as well as an opportunity to develop a social network and meaningfully engage with other people.

One of the most important things that we got from working with Eden Autism, conducting the literature review, and creating the infographic addressing stereotypes around autism is that the experience of having a child with autism is composed not only of challenges but also of unique victories and celebrations. Parents share the accomplishments of their children with other parents which helps form a tight-knit community. Children with autism are different

but that doesn't mean that they are unable to do things like help around the house and vacuum. That is why it is crucial to approach each person with an empirical lantern with the goal of learning about the unique circumstances and habits of the individual. Melinda emphasized the importance of an individualized approach to each person with autism as the key to establishing a productive relationship between the service workers and the individuals with autism. The experience of working with Eden Autism showed once again the importance of utilizing an empirical lantern and an anthropological approach instead of relying on the constructed definitions of normal and abnormal to avoid oversimplifying an individual's experience and contributing to faulty stereotypes.

References

11 Myths About Autism. (2018). Retrieved from

     https://www.autismspeaks.org/blog/11-myths-about-autism.

DePape, Anne-Marie & Lindsay, Sally. (2016). Lived Experiences From the Perspective of

     Individuals With Autism Spectrum Disorder: A Qualitative Meta-Synthesis. Focus on

     Autism and Other Developmental Disabilities. 31. 60-71. 10.1177/1088357615587504.

Hadjikhani, Nouchine. "Deconstructing Scientifically Some of the Myths Regarding Autism."

     Schweizer Archiv Für Neurologie Und Psychiatrie 165, no. 08 (2014): 272–76.

     https://doi.org/10.4414/sanp.2014.00297.

Maureen E. Angell, Hedda Meadan, and Julia B. Stoner. (2012). Experiences of Siblings of

     Individuals with Autism Spectrum Disorders. https://doi.org/10.1155/2012/949586.

Schriber, R. A., Robins, R. W., & Solomon, M. (2014). Personality and self-insight in

     individuals with autism spectrum disorder. *Journal of personality and social psychology*,

     106(1), 112–130. https://doi.org/10.1037/a0034950

Wood, C., & Freeth, M. (2016). Students' Stereotypes of Autism. *Journal of Educational Issues*,

     2(2), 131-140.

Wright, Jessica. (2017). "The Real Reasons Autism Rates Are Up in the U.S." Retrieved from

     https://www.scientificamerican.com/article/the-real-reasons-autism-rates-are-up-intheus/.