Connecticut College American Studies Senior Seminar
“Globalization and American Culture Since 1945” Book Review

Author: Rachel Adams
Title: *Raising Henry: A Memoir of Motherhood, Disability & Discovery*
Publisher: Yale University Press, 2013
Reviewed by: Tricia Guay

The memoir, *Raising Henry*, traces the trials and tribulations of Rachel Adams' struggle to accept, understand, and treat her son's Down Syndrome. The memoir traces the experiences of her disabled child, her family, and herself as they all struggle to come to terms with the realities of raising a disabled child. Before the birth of her second son, Henry, Adams was a tenured professor at Columbia University whose life seemed to be going according to plan. She met her lawyer husband, John, in graduate school, both of whom adored the other. Soon after their marriage she gave birth to her first child, Noah, who was born a perfectly healthy baby. Adams never expected that her second born son, Henry, would be born with Down Syndrome.

Throughout the book Adams explains how she used her academic training to further her understanding of Down Syndrome. She read many books and attended conferences, but was first comforted by the experiences of a friend and colleague, Michael Berube, who is also a parent of a child with Down Syndrome. Adams explains she felt disappointed in her doctors after her delivery because she felt abandoned and uninformed about the disabling effects of Down Syndrome. She reflects on the struggle that she and John experienced during the first few months of Henry's life while learning how to treat their son's disability. When Adams was asked to speak to a group of medical residents, she approached the opportunity as a professor by distributing handouts with certain scenarios and asking for their responses. She concluded that medical students are
not prepared to confront the “difficult and sometimes tragic nature of their work.”

Throughout the book she calls upon her dissertation research that focused on people who defy the medical standards of normalcy, such as Siamese twins. Adams then compares the injustices she recognized between them and Henry on account of their disabilities. Adams states, “I've always believed that the full integration of people with disabilities challenges our ideas about what counts as normal” (p. 85).

Adams honestly describes her most intimate emotions, especially fear, which makes the book resemble a beautifully written journal. She describes her self pity while attending a breast feeding class where all of the other mothers did not have the challenge of feeding an extremely weak child with Down Syndrome, and her sense of accomplishment when she discovered that Henry was consuming more milk than all of the other infants. She states, “I walked out of the meeting elated. I would be able to nurse my baby. Henry had shown the doctors how wrong they were” (p. 55). Adams also relates her fear that Noah will be negatively affected by having a brother with Down Syndrome, admitting she was reluctant to explain Henry's disability to him in fear that he may not view him as a person, and the pressure he may feel to be perfect due to having a brother with a disability.

Her relationships with her sons are central to the memoir, especially as she struggles to accept their differences. While Adams describes Noah's character as extremely independent and admits to the pain she felt when he began to drift away from her, she characterizes Henry as extremely dependent upon her and all of the therapists who aided in his growth. While her sons obviously have very different personalities, they also had different circumstances surrounding their births. When Adams was pregnant
with Noah she decided to receive prenatal testing, but rejected the option while pregnant with Henry due to her age and the risk of breaking the amniotic sack. Her doctor advised her that there were very slim chances of birthing a child with disability and even though Henry was born with Down Syndrome, Adams she later expressed her happiness that she was unaware of Henry’s disability before his birth. She explained that within the medical field mothers are often advised to abort their pregnancies if there is a recognized disability before birth. The medical field viewed Down Syndrome as a burden and doctors believed that a life of Down Syndrome was pointless and only negatively impacted those around them, but Adams’ reflections and insights in her memoir show that while children born with Down Syndrome can cause additional concerns for parents, they can also bring additional joy.

The pressures of maintaining Henry’s medical appointments, helping therapists gain his attention when he was unwilling, and worrying about his development exhausted Rachel Adams and her husband. During parent-teacher conferences at Henry’s pre-school, she and John felt overwhelmed constantly trying to understand the struggles Henry faced compared to his non-disabled classmates. Yet Rachel and John persevered and did everything in their power to give Henry the therapy and exposure he needed to develop to his highest potential. They knew that therapy was crucial to his progression, and successfully fought the system when it stated that Henry was aging out and he would have to be re-evaluated for therapy. Even after fighting these battles, Adams consistently acknowledges he appreciation for the therapists who assisted Henry, and she kindly describes their characteristics and the role they played in Henry’s development.
Despite all of the challenges Adams and her husband faced raising their son, Henry, she also focuses on the indescribably joys that Henry brings to her life. For Henry's third birthday Adams indulged in her hobby, baking, and made triple layered gluten free birthday cake for him and his friends. She was disappointed to see that none of the children were eating the cake due to the sugar free taste, but none of that mattered when she discovered that Henry was fully enjoying the cake and then asked for more. At that moment she had hope because Henry had clearly spoken and she knew that he was going to be capable of achieving more than the limitations that society placed on him once he was stigmatized by his disability. In her life and in her memoir, Adams acknowledges and sympathizes with the challenges Down Syndrome presents to families while also declaring her realization that Down Syndrome does not have to dictate her son’s life.