

Kiley Adams

Graduation Year: Senior

College: Science

Major(s): Biology

Minors(s): none

Scholar Group Membership: Sorin Scholars

Did you received other funding for this project?: no

Could you have completed this project without CUSE funding? No

More details on CUSE funding assistance?

Project Title: Finding India's Missing Disabled Population

Project Location: India

ND Faculty Mentor: Peter Walshe

Project Type: Research

Why did you undertake this project/experience? Deepen your knowledge of a topic or issue, Prepare for national fellowships, Career discernment and/or preparation, Internationalize your Notre Dame experience

Did your funded experience help you:

[Deepen your understanding of your coursework or field of study]: Yes

[Discern your interests and post-bac goals]: Very Much

[Become confident in your ability to set and achieve your goals]: Very Much

[Gain a more nuanced view of local, national, or global communities]: Very Much

[Improve your written and verbal communications skills]:Yes

Tell us about your experience.

My research took me to the 4 corners of India. Starting in Kerala (Southwest corner), the most "developed" state in India, I interviewed professionals at care centers for both adults and children with disabilities. I then moved to one of India's largest cities - Chennai in the Southeast - where I lived at an NGO, Vidya Sagar (VS), a school and therapy center for children with disabilities. Because VS has an outreach program in areas in rural Tamil Nadu, I interviewed with the community based rehabilitation workers there. When not interviewing I helped teach in an Early Intervention classroom with many of the same kids I worked with last year. Next, I traveled to the most rural area in India - Arunachal Pradesh - where I lived with the Bishop of Miao, a small jungle town in the Northeast. There, I learned firsthand the struggles of treating disability in a rural setting by visiting many families of an individual with a disability. These experiences were then contrasted with my final travel experience in Rajasthan, the desert state in the Northwest which borders Pakistan. I lived, worked, dressed, and ate in a rural village with a family of weavers. Because of the overwhelming diversity in India - the language, religion, clothes, and customs change dramatically from state to state - every place I went gave me a new potential answer to my research question. I was exploring, broadly, what barriers exist to treating and identifying individuals with disabilities in rural India. Whereas in Kerala most

answers surrounded familial shame about having a family member not able to be married (as is very important to Kerala's culture specifically), in Arunachal Pradesh the answer was that infanticide is exceptionally common since the area is so rural it truly is not feasible (at the moment) to allow such individuals to continue living. In Tamil Nadu, the most Hindu state, many answers surrounded beliefs that people with disabilities or their parents made a mistake in a past life and now must pay for their actions (and not receive any services). While the specifics of my project changed based on the location, many ideas remained the same. The following quote from a community based rehab worker sums up this idea, "Caring for the disabled in India is confusing. Confusing because the amount which we deeply care for the individual is seldom able to be met by the facilities and resources available. Some people find this disconnect so disheartening they quit looking for such services. But many just choose to care more fiercely." I found time and time again that the interest and compassion to treat peoples with disabilities was present, just the circumstances and resources of rural India made it exceptionally difficult in practice.

Describe the impact this project had, both on you as a student-scholar and on the people you worked with.

My Indian experience was so meaningful because of how many relationships I was able to form. My academic experience there would not have been possible without the numerous families and friends who took me in, fed me, clothed me, and opened up their homes to have me stay there. I learned through these relationships, even more than from my specific research interviews, the beauties and struggles of living in rural India. By extension, I was able to understand firsthand the help disability services in rural India need to make a bigger impact on their communities. I learned how dependent I am as a student-scholar on the hospitality and generosity of others. My path to gaining more knowledge in the field of disability is contingent on the give and take relationship of myself with peoples of other backgrounds and cultures. I look forward to building more relationships and learning alongside these new friendships.

Describe how this experience is connected to your plans as a student or future professional.

I am applying to the Fulbright Research Fellowship to continue research on the Community Based Rehabilitation (CBR) model with Vidya Sagar in Chennai, India. Even if I do not obtain this fellowship, I will absolutely be continuing my academic pursuits in disability rehabilitation and will likely go to medical school to become a pediatric physiatrist in the hopes of expanding care to more children with motor disabilities specifically. In my more immediate future, I will be sharing this summers research at one of the research conferences here at Notre Dame this year.

What advice would you give other students who are planning to pursue similar projects?

Asking questions and listening to the answers is a very narrow part of research. Living, eating, dressing, working, and playing with the peoples to whom your research pertains to is of equal or more importance. Never underestimate the importance of simple human interactions, such as helping to prepare lunch, in the research process. Not only do these actions help gain the trust of the people you will later interact with but they often offer unexpected insights to your initial

