

COTLOW FIELD RESEARCH FUND

Department of Anthropology
The George Washington University
Washington, DC 20052

2006 PROJECT DESCRIPTION FORM

Applicant: Bonnie O. Richard

Title of project: The Changing Cultural Outlook on Disability in Ladakh, India

The Lewis Cotlow Field Research Fund is a GW Anthropology Department fund, established in 1990 as a bequest by the explorer Lewis N. Cotlow to further field work and exploration. All undergraduate or graduate students at The George Washington University are eligible to apply, but preference is given to those in anthropology programs. Funds are to be used for travel, research assistance, and other expenses related to field research.

The deadline for application is 5 p.m. on the first Friday in March of the year for which support is requested. Applications must be submitted in hard copy; no electronic submissions will be accepted.

DESCRIPTION OF PROPOSED COTLOW FIELD RESEARCH PROJECT

I. Personal Information

Name: Bonnie O. Richard

Permanent Address:

Current Address:

Home Phone:

Other Phone:

E-mail:

Degree Sought: MA

Field of Study: Anthropology

Expected Date of Graduation: May 2007

Faculty Advisor(s) for This Project: Barbara Miller, Richard Grinker

Does your proposed project involve the use of a "field language"? Yes

If so, state what it is, and note your degree of fluency in speaking or writing.

My basic knowledge of Tibetan and Ladakhi will allow me to establish rapport and will demonstrate my respect for the local culture. However, I will also use a translator, as the detailed subject matter will be beyond the scope of my conversational knowledge of these languages. At other times, I will use English, as many people in Ladakh speak English proficiently as a second language.

II. Brief Abstract of the Project

Title of Project: The Changing Cultural Outlook on Disability in Ladakh, India

In 100 words or less, clearly state the goals of the proposed research.

I hope to document the changes surrounding the culture of childhood disability in a Tibetan Buddhist region. Focusing on Leh sector of Ladakh, in north India, this project will highlight how the recent introduction of western biomedical-modeled special education programs affect the lives of children with disabilities, their families, and the general community. Namgyal Institute, founded in 2000, provides access to mainstream education for physically and cognitively disabled children, by training teachers and providing transportation. Recently opened in 2006, the Moravian Ability Center provides training to cognitively disabled children who cannot succeed in mainstream educational environments. Through participant observation in homes and classrooms, as well as interviews with educators, I will describe how these communities accept or reject the new programs.

III. Significance of the Project to Anthropology. What is the relationship of the proposed research to other anthropological research in this field and region? (250-500 word maximum)

The information derived from this project will be situated within two main areas of anthropological inquiry: Ladakh and Himalayan studies, and disability studies and medical anthropology.

Ladakh and Himalayan Studies

Although there are, to my knowledge, no studies of childhood disability in Ladakh or the Himalayas from an anthropological perspective, there have been cross-cultural studies of disability in other parts of India (Daley 2004, Rao 2001). Van Beek (2000) and Aggarwal (2001) have contributed literature on identity politics in Ladakh, and Wiley (2004) has published a study of reproduction and infant mortality in Ladakh. Aggarwal notes that development schemes that have sprung up throughout Ladakh often trump traditional values and beliefs with inadvertently offensive notions of progress (2001:563). Since the programs that assist disabled Ladakhis are indigenous efforts (though have some outside financial support), their effectiveness and effects on Ladakhi society are an important line of inquiry.

Disability Studies and Medical Anthropology

While limited, anthropological studies on disability (see for example Ingstad and Reynolds Whyte 1995) demonstrate common themes. These include the results of stigma (such as marginality and social restriction), the influence of western organizations, emic definitions of disability, and the question of location of one's disability (individual, family, or public). Recently, Landsman studied American mothers of cognitively disabled children, specifically looking at the constant negotiation between the biomedical model of disability and the disability rights model (2005). She emphasizes a theme that is also found in some African contexts: social perceptions shape the definition of disability and in turn determine the extent to which opportunities are offered to the cognitively disabled (Ingstad 1995, Helander 1995).

Labeling theory adds an important dimension to questions related to agency and structure. Hahn explains that according to the labeling theory hypothesis, placing labels on people can cause them to conform to the criteria for that label (1997:62). While cognitive disabilities do have biological causes, a diagnosis labeling the individual as such may cause him to conform to certain expectations. The implications of the meaning derived from such a label may extend to affecting the way the individual perceives himself to the way caretakers, educators, doctors, policy makers, and other members of society perceive and behave toward the individual.

Scheper-Hughes and Locke explain that while diseases clearly have a biological reality, they also have a social reality (1986). They employ the term "double" in describing the disease's second reality (1986:137). In much the same way, cognitive disability is not at all exempt from having a separate, social reality that may stigmatize the individual and her family. As Kleinman explains, "biological constructions of the various forms of human misery as health problems are reinforced by societal regulations that can influence all sectors of experience, from the courts to the workplace

to the household" (1995:38).

Cognitive disability has been shown in a variety of cultural contexts to be a shared experience of suffering for the afflicted individual and his family, and perhaps the larger community (Goode 1984; Das and Addakha 2001; Hartley, Ojwang, Baguwemu, Ddamulira, and Chavuta 2005). Das and Addlakha argue that disability and impairment might be understood more effectively through viewing the domestic sphere as not merely private, as previous work might suggest, but rather as "the sphere in which the family has to confront ways of disciplining and containing contagion and stigma" (2001:512). Such an approach would demonstrate that the disability is located "within a network of social and kin relationships" and not merely in the body of the disabled person (2001:512).

IV. Methodology. What are the specific research questions you plan to ask? What data will you collect and how? How will you analyze the data? How do you plan to use these data to address and resolve your research questions? Be specific. (250-500 words maximum)

I will describe how traditional views of disability, based in Tibetan Buddhism, affect the integration of disabled people and their families into social and economic life. I want to find out whether such views have changed in recent years and what the causes of those changes may be. I hypothesize that organizations promoting inclusion of disabled people into society are influential on the experience of raising a disabled child. Through providing educational opportunities, these organizations promote the possibility that the disabled person might contribute to the household as opposed to merely being a lifelong burden. What roles (directly or inadvertently) do organizations play in changing the culturally constructed view of disability?

I also plan to be a participant observer in various home settings. I will spend time in households with disabled children, and for comparative purposes, I will also observe families with able-bodied children. I have been invited to spend time in the home of a family who has a son with Down's Syndrome. During a previous trip to Leh, in 2005, I met various other families (with and without disabled children) who will also host me and give me greater access to everyday domestic life. I hope to better understand what life is like for families with disabled children.

There are six children with cognitive disabilities in Leh who have recently begun attending special education programs at the Moravian Ability Center. I plan to observe these classes, to the extent that the teachers and parents feel is appropriate. I am familiar with the founders of this school, and they have invited me to observe. My goal is to observe the process of educating disabled children (and at times, their parents). I hope to understand the social implications of the center and the work being done there.

Formal interviews with educators will supplement participant observation. The questions I will ask relate to cultural attitudes of disability and disabled persons, as well as attitudes regarding educational opportunities for the disabled.

V. Ethics. Describe (in 150-200 words) how you will ensure that your research project is conducted with attention to the ethical guidelines of the discipline of anthropology (and your project's particular field within the discipline) and the guidelines of GW's Institutional Review Board (if your project involves living human beings). For the former, consult the Web site of the American Anthropological Association and its section on research ethics ([http:// www.aaanet.org](http://www.aaanet.org)). For the latter, review GW's IRB guidelines (<http://www.gwumc.edu/research/human.htm>).

I have familiarized myself with the American Anthropological Association's guidelines for research ethics and understand my expectations as a researcher to the people being studied as well as to other parties such as the academic community and the general public. Specifically, I recognize that the participants in my research must be aware of the nature and goals of the research project, willing to participate, and be kept anonymous unless they clearly state otherwise. I also realize the importance of accurate, unbiased presentation of my data. I will keep these and other ethical objectives in mind at all times while conducting my research, and will strive to keep my project and its goals clear of any questionable situations or grey areas.

I will also follow GWU's Institutional Review Board guidelines for the ethical treatment of human subjects. I will request a waiver of written consent forms for my research with families, but I will seek written consent for my formal interviews with professionals. I will seek to prevent any harm to the participants by being aware at all times of potential risks. While minimal, these risks include emotional stress to parents or caretakers. Such harm may be caused by asking questions about sensitive subject matter, related to their feelings towards their disabled child or the social perception of the disabled child or the family. Therefore, I will not ask questions pertaining to sensitive areas, and will only glean information on sensitive topics if it is freely offered. If any other topics arise in my interaction with the participants, and they become uncomfortable, I will discontinue the discussion so that the participants do not feel obligated to discuss information that causes them emotional stress. I will also be extremely careful with any information I obtain regarding a disabled child's condition. All participants will have pseudonyms in all of my research notes, and therefore every effort will be made to preserve confidentiality of the parents, families, and especially children.

VI. Product. What kinds of results do you expect to come from the proposed research? (E.g., publishable article, presentation at a professional meeting, film, museum exhibit, etc.).

I look forward to presenting my findings at the 2007 Cotlow Conference. I will also produce a publishable article, and will make my findings available to research participants and to the Moravian Ability Center and to Namgyal Institute. Finally, I hope to present a paper on a student panel at the American Anthropological Association meetings.

VII. Schedule. State clearly your timetable of specific research activities.

Week 1: Travel to India, stay overnight in Delhi. Travel to Leh, Ladakh, and acclimate to altitude, re-establish contacts, and recruit families who are willing to participate in research.

Weeks 2-8: I will spend at least 1-2 days per week as a participant observer at the Enablement Center. In addition:

Week 2: Visit with staff at Enablement Center. Discuss research goals and make plans to observe and participate in classes. Interviews with teachers.

Week 3: Participant observation in homes of children with disabilities.

Week 4: Participant observation in homes of families with and without disabled children.

Week 5: Interviews with teachers.

Week 6: Continue participant observation in homes.

Week 7: Continue participant observation in homes.

Week 8: Participant observation with families. Travel to Delhi, then to Washington, DC.

IX. Staff. If others are to participate in the project as investigators or assistants, please give their names and qualifications.

None.

XI. References cited and select bibliography (one page maximum).

Aggarwal, Ravina. 2001. "At the Margins of Death: Ritual Space and the Politics of Location in an Indo-Himalayan Border Village." *American Ethnologist* 28(3): 549-573.

Daley, Tamara C. 2004. "From Symptom Recognition to Diagnosis: Children with Autism in Urban India" *Social Science and Medicine* 58: 1323-1335.

Das, Vena and Renu Adlakha. 2001. "Disability and Domestic Citizenship: Voice, Gender, and the Making of the Subject" *Public Culture* 13(3): 511-531

Goode, David A. 1984. "Presentation Practices of a Family with a Deaf-Blind, Retarded Daughter." *Family Relations* 33(1): 173-185.

Hahn, Robert A. 1997. The Nocebo Phenomenon: Scope and Foundations. *In* The Placebo Effect. Anne Harrington, ed. Pp. 56-75. Cambridge: Harvard University Press.

Hartley, S., P. Ojwang, A. Baguwemu, M. Ddamulira and A. Chavuta. 2005. "How Do Carers of Disabled Children Cope: The Ugandan Perspective." *Childcare, Health, and Development* 31 (2): 167-181.

Helander, Bernhard. 1995. "Disability as Incurable Illness: Health, Process, and Personhood in Southern Somalia." In *Disability and Culture*. Benedicte Ingstad and Susan Reynolds Whyte, eds. Pp. 73-93. Berkeley: University of California Press.

Ingstad, Benedicte. 1995. "Public Discourses on Rehabilitation: From Norway to Botswana." In *Disability and Culture*. Benedicte Ingstad and Susan Reynolds Whyte, eds. Pp. 174-195. Berkeley: University of California Press.

Ingstad, Benedicte and Susan Reynolds Whyte, eds. 1995. *Disability and Culture*. Berkeley: University of California Press.

Kleinman, Arthur. 1995. *Writing at the Margin*. Berkeley: University of California Press.

Landsman, Gail. 2005. "Mothers and Models of Disability." *Journal of Medical Humanities* 26(2/3): 121-139.

Rao, Shridevi. 2001. "'A Little Inconvenience': Perspectives of Bengali Families of Children with Disabilities on Labeling and Inclusion." *Disability and Society* 16(4): 531-548.

Scheper-Hughes, Nancy and Margaret M. Lock. 1986. "Speaking "Truth" to Illness: Metaphors, Reification, and a Pedagogy for Patients." *Medical Anthropology Quarterly* 17 (5): 137-140.

van Beek, Martijn. 2000. "Beyond Identity Fetishism: "Communal" Conflict in Ladakh and the Limits of Autonomy." *Cultural Anthropology* 15(4): 525-569.

Wiley, Andrea S. 2004. *An Ecology of High-Altitude Infancy: A Biocultural Perspective*. New York: Cambridge University Press.

XIII. Permits. Various permits may be necessary to conduct the proposed research (e.g., research visas, research permits, antiquities permits, Historical Preservation Committee approvals, health forms, research on human subjects forms). Anyone planning to conduct research with humans - even if through an impersonal survey form or using data about humans collected by someone else - must fill out and submit a set of forms about the "protection of human subjects" before undertaking the research. In most cases, if you have been thoughtful about ethical aspects of your research, and you convey this clearly on the forms, the Committee will speedily approve your project. The forms are available on the Web: <http://www.gwumc.edu/research/human/htm>. Unless you are doing biomedical research, you should use the forms labeled "non-medical." If you have questions, there is a phone number on the Web to call, but please do so only after carefully reading the instructions, trying your best to proceed according to the guidelines, and seeking advice from anthropology professors. If you have the requisite paperwork, attach copies to this application; if you do not yet have it, summarize the steps you have taken to obtain it. If no permits or committee approvals are necessary, state that below.

I have begun the process for approval of human subjects research with GWU's Institutional Review Board. No other permits are required for this research project.