1. Personal Information

Applicant’s name: Alicia O’Brien

Degree sought: Bachelor of Arts degree

Field of study/major/minor/concentration: International Affairs, Concentration in Contemporary Cultures and Societies, and Anthropology

Expected date of graduation: May 2011

Faculty advisor(s) (who have served as your mentor or mentors for this proposal): Dr. Frances Norwood, Dr. Barbara Miller

2. Language Skills

Does the proposed project involve the use of a “field language”?

No

3. Title of the Project and Abstract

Project Title: Describing the Gap: The Impact of Identity and Culture for Individuals with Cognitive Disabilities After Transitioning from School

Abstract of the Project (provide a summary description of the project’s goals, location, methods, and relevance to anthropology) [80 word maximum]:

This research will explore individuals with cognitive disabilities in Westminster, MD, and how they negotiate transitioning from school to adult life. Parents, post-secondary and vocational education instructors will be interviewed in an effort to understand how, and in what environment, individuals navigate this process. Participant observation in the classroom and during vocational training will provide contextualized interview data. My research will impart information on understudied impacts of identity and culture on lives of the cognitively disabled transitioning to adult life.

[Word Count: 80]

4. Description of the Project (describe your overall research goals, what the project is generally about, and where you will conduct the research and why) [250 word maximum]:

Preparation of young adults with disabilities for a world beyond high school has become a growing interest among educators, parents, and professionals involved in this unique part of society. This
stage of life is commonly referred to as transition. Little is actually known regarding transition programs and their impact on cultural and identity formation of people with severe cognitive disabilities. Most research on transition is comprised of quantitative post-school outcome surveys that utilize large samples to assess general outcomes. For example, these studies examine vocational status, number of hours worked, wages earned, etc. My research promises to explore how the disabled think of themselves throughout transition, how this period effects the family as a whole, and how the individual, the parent, and the program staff work together to make transition successful and meaningful to all involved. I will investigate identity construction and the culture of disability of persons with cognitive disabilities as they transition into adulthood through fieldwork in Westminster, MD at Carroll Springs (a post-secondary school) and The Arc (an organization that advocates for and provides services for persons with cognitive disabilities following graduation). Each facility works to provide support to people with developmental disabilities and their families in Carroll County, Maryland. Both are well established and respected institutions. Through conducting participant observation, unstructured and semi-structured interviews, at these sites my research will build from and expand upon anthropological studies on individuals with severe cognitive disabilities.

[Word Count: 237]

5. Significance of the Project to Anthropology (in this literature review describe how the proposed research relates to other anthropological research on the topic, and/or region as relevant; use American Anthropological Association style for works cited--no footnotes) [500 word maximum]:

Anthropology and Disability: Common themes and views

Activists are advancing a social model of disability, claiming it is not an “individual’s impairment but rather socially imposed barriers that construct disability as a subordinate social status and devalued life experience” (Berger 2008:648). A growing source of cross-cultural literature concentrates on disability to support this model. In anthropology, existing research illuminates major stressors of everyday life for a person with disability, such as stigma, self-determination, definitions of disability, etc. that play a role in the aforementioned social model. (Wehmeyer 2001:379). It is clear from this work that social perceptions shape the definition of disability not only for the public at large, but also for the person living with disabilities (Ingstad 1995). This definition and societal view of disability influences the agency of individual, the extent to which they utilize resources available to them, and how they identify themselves as adults living with disabilities.

In addition to this, there is research in medical anthropology that has a ‘therapeutic theme’ in terms of disability (Shuttleworth 2004:142). By defining disability as a disease state, medicine and other like disciplines see a need to cure and restore the disabled individual to as nearly a normal existence as possible. Yet, disability confounds the assumption of such a transformation; for the disabled person in U.S. society, hope is often not found in a cure, but rather a self-determining role in society. Medical anthropologist Nancy Scheper-Hughes asserts that while diseases have a biological foundation, they also have social facets (1986:137). Cognitive disability is not exempt from having a social component. Individuals may be marked as different by others and socially devalued because of this difference, and as described by Daley and Thomas, this structures self-worth and self-esteem. From these viewpoints, disability obviously needs to be focused on individuals’ abilities and celebrate them as beneficial members of society.
While the views of the disabled in other countries, as well as the study of specific groups within the United States—such as sibling cases, athletes, etc.—are important to the study of disability anthropology, there is a fundamental piece missing to the research being done, namely, study of the transition period for individuals with cognitive disabilities. During successful transition from school to adult life, individuals with cognitive disabilities will develop a perspective of personhood, of self-identity, as adults that allows them to define themselves as part of society. What is less than clear, however, is how successful transition programs are supporting this important shift to adulthood.

Current transition literature for individuals with severe cognitive disabilities largely consists of researchers describing “how to” implement transition programs, as opposed to focusing on the individuals experience of these programs (Kraemer 2001:423). This time of life is vital; it is necessary to explore how transitional processes provide culture-specific values and expectations about work, community integration, role expectations, and social functioning (Rueda 2005:412). Research needs to be done during transition to learn how it impacts the lives and hopes of people with cognitive disabilities, how they view themselves in general and in relation to others with and without disabilities, and how they are supported through this.

6. Methods (clearly outline or list your research questions; describe the data you will collect and how you will collect it; discuss your analytical methods; and show how the data will address the research questions) [300 word maximum]:

Through observing classes/activities, interviewing parents, and interviewing program staff, I will explore identity of cognitively disabled young adults in transition, their aspirations, and how they are supported. I am interviewing staff and parents, because permission to interview persons with moderate to severe cognitive disabilities requires more time than is possible given the length of the research project. They will be sources that provide important information about the transition process.

To contact parents, research sites will (e)mail a letter of invitation on my behalf to all parents asking for interview volunteers. I obtained permission to interview instructors at each research sites. In the process of snowball sampling, I will ask participants already committed to my study to recommend other invested professionals. Avoiding sample bias, I will request more than one other expert from each contact.

With completed data collection, I will analyze transcribed interviews and code them for common themes and patterns. Measuring the frequency of each code will aid my effort to see connections between codes. Through this I will obtain knowledge of commonalities and differences of perspectives. Analyzing my notes with coding will present a closer look at what participants were actually trying to convey and say about how they feel and what they think. I will compare and confirm this analysis with observational notes, i.e. what people do, in order to give much of the interviews situated and meaningful context.
Draft Interview Guide for Parents/Caregivers/Staff

Describe the individual and a typical day/week.

Describe the program in which the individual is currently enrolled.

How does the individual feel about him/herself?

What are your concerns/hopes given the individual’s current situation?

Compare and contrast your concerns/hopes to theirs.

How do you work with the program to move toward your goals, address your concerns, and support your child in their transition?

How do you/the program promote a feeling of agency/support?

[Word Count 299]

7. Research Ethics (describe how you will ensure that your research project is conducted in accordance with anthropology guidelines and the guidelines of your particular field within anthropology, and in the case of “Human Subjects Research,” according to the criteria of GWU’s Institutional Review Board. For the former, consult the Web site of the American Anthropological Association (http://www.aaanet.org). For the latter, discuss requirements with your faculty mentor and/or with Professor Barbara Miller, the IRB rep in the Anthropology Department. Most student projects involving living humans fit in the IRB category of “excluded” meaning that IRB forms do not need to be submitted, if they follow AAA ethical guidelines in terms of informed consent and avoidance of harm to participants, do not involve medical topics and do not identify particular individuals. In some instances, IRB approval does need to be sought, usually in the “expedited” category.” Information on these categories is also available at http://www.gwumc.edu/research/human/aboutus/html [150 word maximum]:

I will comply with the American Anthropological Associations code of ethics. When participants possess complete knowledge of my objectives, how I will use data, their right to anonymity and withdrawal of participation at any time, I will seek oral consent and begin research. Under circumstances of withdrawal, information gained will be removed immediately from my research.

I intend to avoid causing harm to anyone involved, and anticipate no tension or conflict. I received consent from administrators of the programs with which I will work, and will seek additional consent if I work with other programs within my research sites. Families of the cognitively disabled individuals will grant permission to those working with their children to speak with me about details of their lives. On my part, I will submit my proposal to GWU's IRB.

I have begun the preliminary stages of the submission process, and completed CITI and HIPPA training.
[Word Count 150]

8. Research Product (discuss how you will use and present your findings including, for example, a presentation at a professional meeting, a film, a museum exhibit, a publishable paper, a thesis) [150 words maximum]:

At the completion of this project I will produce a presentation for the 2011 Cotlow Award Conference that summarizes my findings and possible questions that arise form the research. I
will also make my findings available to research participants, and attempt to do this in the form of a publishable paper.

This research combines my interest in Anthropology and my long-term devotion to those with intellectual and developmental disabilities. I hope to create a more comprehensive study of this crucial point of their lives, and to continue in this field of research in the future as part of graduate work in Anthropology.

[Word Count 102]

9. Timetable (briefly describe the schedule of your research activities week-by-week or as appropriate):

- 22 weeks of research between April 15-September 9, 2011
- Minimum number of interviews (at about 1 hour/interview): 25 staff/instructor/administrator and 10 parent interviews
  - Weekly transcription if interviews: 10-12 hours a week
  - Throughout the research period I will contextualize data through participant observation with the classrooms and general facilities of research sites. During participant observation I will conduct informal and unstructured interviews with my contact (i.e. the staff member, administrator, or instructor) in order to clarify what I am observing and to frame the situation taking place.

  April: Weeks 1-3 (Introduction to Carroll Springs)
  - 3 staff interview
  - 1 parent interview

  May: Weeks 4-7
  - 4 staff interviews
  - 4 parent interviews

  June: Weeks 8-11 (Introduction to The Arc)
  - 4 staff interviews
    - 3 parent interview
  - 8 staff interviews

  July: Weeks 12-16
  - 8 staff interviews

  August: Weeks 17-20
  - 6 staff interviews
  - 2 parent interview

  September: Weeks 21-22
  - Any additionally needed follow-up interviews

  September-October
  - Complete synthesis and analysis of data

10. Budget Amount and Projected Expenditures

Total Amount Requested: $ 765

Projected Expenditures (list the expenditure categories for your project, for example, transportation--international, domestic, local; room and board; and research supplies). Funds from a Cotlow award cannot be used for tuition, academic fees, or for purchasing equipments such as a laptop or camera [awards range from a few hundred dollars to $1800]

Gifts for parent participants: $150
  - Gift card to Target for parent interview participants ($15/card for 10 interviews)

Informal Gifts for staff participants: $200
  - Funds to provide staff interviewee with lunch, tea/coffee during interview. ($8 for 25
Transportation: $315
- Travel to and from Maryland and Washington, DC via metro. (30 trips at $5.50 round trip.)

Informal Gifts for classroom participants: $100
- Funds to bring gifts and food to classroom to build rapport with staff and students. The director of the Vocational Program at The Arc suggested this. ($5 a week at 20 weeks of classroom involvement)

Room and Board: Self-provided

1. Staff (if others are to participate in the project as researchers or research assistants, please give their name and qualifications): None

2. Outside Financial Support (list any other sources of funding for the project, either obtained or applied for, with amounts and restrictions): None

3. References Cited/Select Bibliography (list the sources you have cited in the proposal and/or used as background research. Use the style defined by the American Anthropological Association [see http://aaanet.org]; list a minimum of 10 sources cited to a maximum of one page; more than 10 references are expected in proposals submitted by MA and PhD students).


14. **Permits** (demonstrate that you have, or are seeking, any necessary permits such as a research permit, a research visa, an antiquities permit, letter of welcome from an institution, etc. Attach copies to this proposal).

Please see letters of support and welcome from Carroll Springs and The Arc of Carroll County.