PROJECT TITLE: The Intersectionality of Race, Culture, and Disability within the Navajo Family

INVESTIGATORS: Jocelyn Esquer

ACADEMIC UNIT: College of Educational Studies

FUNDING AGENCY: N/A

APPROVAL DATE: 5/5/11

APPROVAL PERIOD: FROM: 5/5/11 TO: 5/5/12

FOR RESEARCH INVOLVING HUMAN SUBJECTS:
The Institutional Review Board has reviewed the proposed use of human subjects in the project identified above and has determined that:

a) The rights and welfare of the subjects are adequately protected; the risks are outweighed by potential benefits; the informed consent of human subjects will be obtained by methods that are adequate and appropriate.

b) Type of Consent: WRITTEN: [X] ORAL: [ ] WAIVED: [ ]

c) Research involves use of: [ ] Minors [ ] Students [ ] Disabled
   [ ] Pregnant Women [ ] Patients [ ] Elderly
   [ ] Existing Records

PRINCIPAL INVESTIGATORS PLEASE NOTE:
1. All unanticipated adverse reactions encountered on any study must be reported in writing to the Institutional Review Board within 24 hours of their occurrence.
2. If significant modifications of this approved study are made, the Institutional Review Board must review them prior to initiation.
3. The principal investigator is responsible for retaining the original signed consent forms for 5 years after completion of the study.
4. All approved Informed Consent forms given to subjects must have the Institutional Review Board number and expiration date on the first page of the form and approval stamp on the first and last page of the form.

Signature: ____________________________
Dr. Fran C. Dickson, IRB Chair

APPROVED
FDICKSON 05/10/11

APPROVED
WINN 05/05/11
APPLICATION TO INSTITUTIONAL REVIEW BOARD
for REVIEW and APPROVAL of
RESEARCH WITH HUMAN PARTICIPANTS

TITLE OF PROJECT: The Intersectionality of Race, Culture, and Disability within the Navajo Family

DATE OF SUBMISSION: 03/15/2011

PROJECT TYPE: New [X] Continuation [ ] CUIRB # _________ Other [ ] __________

PRINCIPAL INVESTIGATOR(S):

Jocelyn Esquer PhD candidate College of Educational Studies
Name Position Academic Unit
esque103@mail.chapman.edu 714-686-7790
E-mail Address Phone #

CO-INVESTIGATOR(S):

N/A N/A N/A
Name Position Academic Unit

E-mail Address Phone #

FACULTY SPONSOR/CO-INVESTIGATOR:

Dr. Phil Ferguson Professor College of Educational Studies
Name Position Academic Unit
pferguson@chapman.edu 714-744-7617
E-mail Address Phone #

FUNDED: [X] No [ ] Yes N/A
Funding agency(ies); type of funding; grant number

PROJECT DURATION: (cannot exceed 1 year) ___ Year ____________

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CONFLICT OF INTEREST: Are there any conflicts of interest or potential conflicts of interest between the P.I. (and his/her co-investigators, if any) and the involved funding source or device provider?
[X] No [ ] Yes

If this project is being reviewed by another IRB, submit a copy of their review/approval with this application and explain why another board is reviewing your application.

Attached is the procedural guidelines for the Principal Investigator from the Navajo Nation Human Research Review Board. Receiving permission to perform research on the Navajo reservation is a much more involved process than required by most research activities. The tribe is very cautious regarding what kinds of research are allowed, and understandably, numerous steps are now instituted to ensure the protection of the Navajo people and the integrity of their culture.

For evaluation of your project, indicate by a [X] whether the following are involved:

[ ] Patients as subjects
[X] Non-patient volunteers
[ ] Students as subjects
[ ] Trainees as subjects
[ ] Minor subjects (less than 18 years)
[ ] Subjects whose major language is not English
[ ] Mentally disabled subjects
[ ] Mentally retarded subjects
[ ] Prisoners, parolees, or incarcerated subjects
[X] Subjects studied at non-Chapman locations
[ ] Subjects studied at Chapman-affiliated hospitals
[ ] Subjects in the Armed Services (active duty)
[X] Filming, video-, or voice-recording of subjects
[ ] Department subject pool
[ ] Pregnant women
[ ] Data banks, data archives and/or registration records
[ ] Subjects to be paid

THE PRINCIPAL INVESTIGATOR MUST ASSURE THE INSTITUTIONAL REVIEW BOARD THAT ALL PROCEDURES PERFORMED UNDER THE PROJECT WILL BE CONDUCTED BY INDIVIDUALS LEGALLY AND RESPONSIBLY ENTITLED TO DO SO, AND THAT ANY DEVIATION FROM THE PROJECT (E.G., CHANGE IN PRINCIPAL INVESTIGATORSHIP, RESEARCH METHODOLOGY, SUBJECT RECRUITMENT PROCEDURES, ETC.) WILL BE SUBMITTED TO THE CUIRB FOR ITS APPROVAL PRIOR TO ITS IMPLEMENTATION.

NOTE: Applications and any additional material requested by the CUIRB will not be processed unless legible, properly prepared, and signed personally by the Principal Investigator, Sponsor (if applicable), and the Principal Investigator's supervisor or department/division chair.
I acknowledge that all procedures will meet relevant local, state, and federal regulations regarding the use of human subjects in research (CUIRB Institutional Assurance Concerning Human Research).

[ ] I have completed the NIH Certification and included a copy with this proposal
[ X ] NIH Certificate currently on file in the office of the IRB Chair

Signature of Principal Investigator

Signature of Faculty Sponsor (if applicable)

Date: 3/28/11

Signature of Department Chair

Date: 4/7/11

This one is ready

for: Don.

Martin

Dickson

Chair

No signature needed

OK

Don
Please insert your answers to the following:

1. Describe the rationale for this study.

My major argument in conducting this study is that one way of improving the education and other types of intervention programs for children with disabilities and families of individuals with disabilities on the Navajo reservation is to understand and realize the local Navajo need, local Navajo Knowledge, and local Navajo experience. In other words, this study is based on the premise that the success of educational and other intervention programs depends to a great extent on the current experiences and perceptions of Diné families living on the Navajo reservation with children identified with a disability. In the absence of sufficient information about the experiences and perceptions of Diné families written from a Diné account, it would be likely that current programs and interventions are constrained by the histories, priorities, and writings of Scholars from the dominant Eurocentric perspective. Therefore, I as a Diné woman I will seek to understand, describe and interpret the experiences and perceptions of Diné families living on the Navajo reservation who have a child identified with a disability.

2. Describe the subject population.

It has been noted that investigators who value the importance of minorities in research have more success with minority recruitment (Williams & Corbie-Smith, 2006). The researcher of this study will take special care in recruiting rural participants from two population centers on the Navajo Nation reservation. Public announcements in the form of a presentation of the procedures and proposed benefits of the study will be used in the two population center chapters houses (analogous to counties) to obtain approving chapter resolutions and to disseminate information at the beginning of the study to chapter members. In addition, the researcher will make a point of establishing a trusting relationship with the community representatives where Navajo families can be found by attending the local chapter meetings. Developing these trusting relationships will be important, because they may not only give direct access to potential participants who come into these places, but will also create future relationships.

Purposive and snowball sampling techniques, in addition to word of mouth will be utilized for this study. Participants will need to meet specific inclusion criteria for the study. The use of snowball sampling will allow for the selection of additional participants through referrals from those families who are participating in the study or from those who are familiar with the study (Polit & Beck, 1994).

An important recruitment tactic may be word-of-mouth communication about the study.
from Diné families who plan to participate or have participated already. Word-of-mouth was
defined as someone hearing about the study from a family member, friend, coworker, study
participant, or another source trusted by that particular individual. The effectiveness of word-of-
mouth has been underrated, though several researchers (Lee et al., 1997; Peck, Sharpe,
Burroughs, & Granner, 2008) noted that word-of-mouth is often more effective than other
strategies in recruiting individuals, particularly minorities. Word-of-mouth and snowball
sampling are similar strategies that can be used to locate a hidden population to whom it may be
challenging to gain access. However, the difference between the two recruitment strategies is
that true snowball sampling would begin with a randomized selected sample from a population,
and then each participant would be asked to give a reference of someone who meets the
eligibility criteria (Goodman, 1961; Sudman, 1976).

Conversely, the word-of-mouth strategy that will be used in this study will start with
community gatekeepers and those who participate in the study to communicate the details of the
study to others. Word-of-mouth and social networking can decrease anxiety and distrust that may
be present initially when potential participants hear of a study (Hooks et al., 1988). The strategy
of word-of-mouth is particularly successful among populations with strong cultural values and
for informal communication, such as with Indigenous people (Jones, Steeves, & Williams,
2009).

The criteria for the participation in the study are the following: (a) self reported Diné, (b)
the Diné family has a child with a disability, (c) the child has been identified as eligible to
receive special education services under Part B and C of the Individuals with Disabilities
Education Act (IDEA, 2004), (c) the Diné parent or guardian is the primary caregiver and lives
on the Navajo reservation, and (d) able to provide informed consent.

All participants will be self reported Diné individuals living on the Navajo reservation who
have a child with an identified disability. The Diné of the Navajo Nation may be considered a
vulnerable population due to: (a) decreased access to care, (b) diminished autonomy, (c)
existence of historical prejudice and trauma as the result of colonization, and (d) historically
defined as a population vulnerable to exploitation and harm within research.

The rationale for doing research with this special population is that the absence of research
from a Diné philosophical and cultural perspective, as it relates to disability, is a major deterrent
to the improvement of education, inclusion, and intervention programs as well as research in
these areas. By subsuming disability studies under a dominant, Eurocentric perspective, the
applicability of the research is immediately limited as it ignores the varying influences that
historical, social, economic, and political factors have on individuals with disabilities from
diverse cultures. In other words, the way we understand disability and the way we learn about it
affects the way we respond to individuals with disabilities in our respective social environments
(families, schools, and so on).

For data collection, the study will include approximately 3-5 adult participants. Rossman &
Rallis (2003) suggested 3 to 5 participants are appropriate for qualitative studies using
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phenomenology as a basis for understanding a group of individuals such as this one.

3. **What will the procedure be like from the study participant's point of view?**

Each participant will be informed about the objectives of the study in general. In addition, they will be informed that no harm will come to them as a result of their participation in the study and that they have the right to refuse to answer some questions or all questions in the interview. Furthermore, the participants will be informed that their identities will remain confidential in the presentation and discussion of the results of the study.

Each participant will be given a consent form that they must sign before discussion or data collection begins. This study will use semi-structured interviews to collect data. There will be a total of three interviews or conversations with each participant.

This study will follow what Seidman (1998) calls the three in-depth interview technique for the phenomenological data gathering process. The initial face-to-face interview will be conducted at the most comfortable location and most convenient time for the participant. This interview will focus on the personal life history of the participant relative to the topic; focusing on past experiences up to the present. A semi-structured interview guide based on the research problem, review of relevant professional literature, and relevant studies in a similar area (see Appendix A) will be used. Every effort was made to make the interview guide flexibly structured so that the parents will express their experiences in their own terms (Gall, Gall, & Borg, 2003; Kvale, 1996). In addition consultation with my research supervisor, who has extensive experiences in research methodology and in working with families of children with disabilities, will be ongoing as I use the semi-structured interview guide. The second interview will focus on bringing the life story of the participant into the present; with focus on specific details about the participants’ current experiences with the topic. The third and final interview will be a follow up interview with each participant to seek clarification of the participants’ responses, reflect on the meaning of their experiences, verify data analysis with the participant, gather additional information from the participant, answer any questions posed by the participant and join the two narratives to describe the individuals lived experience with the topic.

The researcher will conduct two of a total of three interviews face-to-face at the location desired by the participant. Creswell (2003) explained the research should be conducted in the natural setting which “enables the researcher to develop a level of detail about the individual or place and to be highly involved in actual experiences of the participants” (p. 181). The third interview will be conducted via telephone, email, or face-to-face if the participant prefers and is most comfortable with. Each interview will be recorded using a digital recorder. Before using the recorder the participants will be informed about the objectives of using the digital recorder and they will be asked about their willingness to be recorded. In addition, to recording the interviews, some notes will be taken in a logbook.

Jocelyn Ann Esquer is the principal investigator of this research study, is a Diné woman from the Navajo reservation, a parent of a child with an identified disability, and an early childhood special educator. As the principal investigator she will conduct all the interviews,
transcribe all audio data obtained and analyze all the data under the supervision of her faculty advisor and dissertation chair, Dr. Phil Ferguson. Dr. Ferguson will serve the role of peer debriefer to facilitate the researcher's consideration of methodological activities and provide feedback concerning the accuracy and completeness of the researcher's data collection, data analysis and interpretation procedures. This process will be an ongoing process throughout the research study.

4. **Describe and assess any potential risks and/or stressful procedures (physical, psychological, social, legal, or other) and assess the likelihood and seriousness of such risks.**

    Should a participant experience any emotional stress due to the content of the conversation, or questions asked I will stop the conversation and remind the participant that they are free to leave the room at any point during the conversation. If the participant chooses to continue I will then ask a different question so as to move the conversation in a different direction. If I perceive the participant to be experiencing any stress throughout the discussion, I will stop the conversation and ask if they would like to terminate the conversation for the day or leave the study entirely.

5. **Describe the consent procedures to be followed, including how and where informed consent will be obtained.**

    Upon approved human subject consent from Chapman University as well as the Navajo Nation Human Research Review Board public announcements in the form of a presentation of the procedures and proposed benefits of the study will be used in the two population center chapters houses (analogous to counties) to obtain approving chapter resolutions and to disseminate information at the beginning of the study to chapter members. In addition, the researcher will make a point of establishing a trusting relationship with the community representatives where Navajo families can be found by attending the local chapter meetings in an effort to facilitate the likely hood of the word-of-mouth strategy and social networking. Once a potential participant contacts the researcher they will be informed about the objectives of the study in general. Then, if the potential participant is comfortable and would like to discuss the study in person and more in depth a meeting time and meeting place of their choosing will be scheduled. At which point the researcher will present the significance of the study, purpose of the study, data collection methods, potential for emotional distress, overview of the interview guide questions, and an explanation of informed consent and consent process. The researcher will inform the potential participant that they can take the time needed before deciding to consent to participation or if they choose potential participants may sign the informed consent form at that time.
Once informed consent is obtained initial interviews will be scheduled and conducted with 3-5 self identified Diné adults who have a child with an identified disability. Participants will be interviewed face-to-face initially. The location and time of the face-to-face interviews will be decided by the participant. Prior to each interview the participants will be provided an overview of the study and a copy of the consent form allowing them to review the documents and to ask questions about the study. Upon their consent to participate a time and place will be scheduled for the interview.

All consent forms will be held separate from the data collected therefore disconnecting data from the participants' names. The digital recordings will be used only until fully transcribed and will then be destroyed so the voices of participants will no longer be able to be used to identify the individual.

All interview data will initially be recorded on a digital recorder. I will download the conversations onto my laptop and keep until the conversations are fully transcribed. Once they have been transcribed the conversations will be deleted. The transcribed conversations will be saved on a private laptop to which I only have access. Once the study has been completed, all transcriptions will be held in a locked file separate from the individual consent forms.

6. Describe the procedures (including confidentiality safeguards) for protecting against or minimizing potential risks and an assessment of their likely effectiveness.

There are no anticipated risks involved in this study. However, there is a slight risk of emotional distress to participants. The study asks participants to discuss their experiences of having a child with an identified disability and is therefore potentially stressful because it could bring up intense emotions. Great consideration was given to the questions in the interview guide as to not embarrass or cause discomfort to participants.

In order to minimize the risk of distress, participants will be made aware of the content of the discussions when they arrive. Prior to the data collection process, I will acknowledge the importance of the participants voice in the conversation and that we all are from different backgrounds, have different experiences so therefore everyone has different views on this discussion. This will hopefully assure participants that I truly respect their opinions and contributions to the discussion. Also, all participants will be reminded that participation is completely voluntary and if they choose to leave at any point they may. If such an incident occurred, I will report it to the Chapman University IRB chair, Navajo Nation Human Research Review Board chair, as well as my faculty advisor.

7. Assess the potential benefits to be gained by the individual subject as well as benefits which may accrue to society in general as a result of the planned work.

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This study could shed light on what practices and beliefs interact with personal and social contexts to influence a Diné family’s response to the obstacles and stressors associated with the presence of a disability and definition of a disability. Additionally, findings from this research will contribute to the literature associated with experiences of parents and other caregivers who have a child identified as having a disability. These research findings will also improve future development of service provision for Diné families of children with a disability on the Navajo reservation. Society will benefit from this research, as the results could allow for the concept of disability to take on a new meaning and a transformative potential when viewed within an indigenous perspective, especially among those living traditional lives in Indian Country. Cultures such as that of the Diné, can offer important insights into what may happen when an individual’s sense of self or identity are unquestioned rights, a perspective that is grounded in the Navajo concept of ‘hózhó’. Hózhó in this context means being at one with your environment and synergistically links you, in such a way that your life complements and harmonizes with all around you.

8. **Describe the source of materials being used in the research (i.e. specimens, records data, whether to be obtained or already existing).**

Participants will be asked to participate in three interviews each lasting about a hour with the researcher. The participants will be asked to respond to and discuss semi-structured interview guide questions or situations. The only equipment used will be a digital recorder, and field journal that all participants will be aware of.

9. **Describe how and when you intend to provide feedback to the study participants, participating organizations.**

In an effort to assure trustworthiness of the data and data analysis member checking will be utilized. Member checking can be defined as the process whereby participants have an opportunity to give their input into the data and its interpretation. This procedure allows the participants to correct errors of fact or interpretation. The process also can verify that the interpretation has reflected the participant’s perceptions. Member checking also informs the researcher of sections that may be problematic for either personal or political reasons. The end result of the member checking is growth in everyone’s understanding of the phenomena. The process of member checking will be ongoing during the data collection and analysis phase of the research. It will be formal and informal. At the end of all the interviews and after preliminary analysis has been completed the participants will be encouraged to review transcriptions and data analysis.

In addition to sharing data with participants the Principal Investigator shall conduct data analysis and present any preliminary findings to the NNHRRB as outlined in the Data Analysis and Preliminary Findings Phase of the NNHRRB review and approval process. During this phase, the Principal Investigator shall analyze the data and develop the preliminary findings into a presentation and provide the same to the NNHRRB during its regularly scheduled meeting. I will present my findings to and discuss them with individual chapters in which the data was

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collected, the Navajo Nation agency which may be able to use the data and findings to influence policy on the reservation, as well as other Navajo Nation officials.

10. **Describe the use of the data obtained from this study.**

   Utilizing the Dissemination Plan outlined by the Navajo Nation Human Research Review Board, the principal investigator will provide presentations to the chapters, schools, tribal divisions and tribal programs regarding the data findings. Findings shall be presented to all officials and programs that provided initial support and approval.

   In addition the principal investigator will develop the data into a proposed manuscript for publication. The principal investigator as the first author will submit a completed manuscript in an approved publishable format as outlined by the Navajo Nation Human Research Review Board and adhere to the NNHRRB approval process. Upon publication, the PI will submit three copies of the publication to the Navajo Division of Health as requested by the NNHRRB. One copy is filed, another is given to the partnering program and the other is reserved for the Navajo Nation Data Resource Center.

11. **Attach any recruitment advertising.**

    - Recruitment Letter

12. **Attach consent forms (and assent forms if children are the study participants).**

    - Informed Consent for adult participants

13. **Attach all forms that will be given to study participants.**

    - Research Participants Bill of Rights
    - Semi-structured Interview Guide for Participants
    - Informational Letter for Research Participants

14. **Describe any conflicts of interest or potential conflicts of interest between the Principal Investigator (and his/her co-investigators, if any) and the involved funding source or device provider.**

    N/A
HELPING FAMILIES OF CHILDREN WITH DISABILITIES ON THE NAVAJO RESERVATION

RESEARCH OPPORTUNITY!!!

Hi, my name is Jocelyn Esquer. I am looking for a few individuals who would be interested in helping me with a study I am doing on the experiences and perspectives of Navajo families who have children with disabilities. My hope is that the results of my study will help improve the educational programs and other supports that would be especially helpful to Diné families living on the Navajo reservation. As a Diné woman myself, I want to describe and understand the local Navajo experience, the local Navajo need, and the local Navajo Knowledge so that our unique history and perspective can be more fully reflected in services offered to children with disabilities and their families.

CHARACTERISTICS NEEDED

Specifically, I am looking for volunteers who are

(a) Diné
(b) Adult (over 18)
(c) Have at least one child receiving special education services and for whom they are the primary caregiver
(d) Lives on the Navajo reservation

If you meet these characteristics, I hope you will consider helping me with this important study. If you think you might be interested, please contact me for more information about the time involved and how the study would actually work. Here is how to reach me:

E-Mail: esque103@mail.chapman.edu
Phone: 714-686-7790

THANK YOU IN ADVANCE FOR YOUR HELP!
March 15, 2011

Dear Study Participant,

As a PhD candidate in Education in the College of Educational Studies at Chapman University, I am conducting a study that explores the experiences and perspectives of Diné families living on the Navajo reservation who have a child with an identified disability. It is my hope that understanding more about the experiences and perspectives of Diné families will help service providers to provide relevant services and support that values the Diné families unique socio-cultural factors. This understanding and valuing can make service provision more meaningful for Diné families and their children with an identified disability.

Qualitative data will be gathered through observations, interviews and document collection of parents over a one-two month period. I am asking your assistance in the study by participating in a total of three interviews; each interview will take approximately 60 minutes and will be set up at dates and times convenient for you. If you agree to participate in the interviews, each one will be audio taped for subsequent transcription, and you may be assured that it will be completely confidential. Upon transcription of the taped interviews, audio recordings will be destroyed. No names will be attached to any notes or records from the interview. All information will remain in locked files accessible only to the Principal Investigator (researcher) and her faculty advisor. No one other than the aforementioned will have access to the interview information, observation data or field notes. You will be free to stop the conversation and withdraw from the study at any time. Further, you may be assured that the Principal Investigator is not in any way affiliated with the local schools, local school boards, or any Navajo Nation tribal government agency.

The Principal Investigator, Jocelyn Ann Esquer, or her faculty advisor, Dr. Phil Ferguson is available at Chapman University in the College of Education Studies at 714-744-7617, to answer any questions you may have. Your participation would be greatly valued.

Respectfully,

Jocelyn A. Esquer
Researcher/Doctoral Candidate
Chapman University
714-686-7790
Esque103@mail.chapman.edu
INFORMED CONSENT

INFORMATION ABOUT:
The Intersectionality of Race, Culture, and Disability within the Navajo Family
CHAPMAN UNIVERSITY
ONE UNIVERSITY DRIVE
ORANGE, CA 92866

RESPONSIBLE INVESTIGATOR: Jocelyn Ann Esquer

I have been asked to participate in a research study that seeks to explore and describe my perceptions and experiences as a Diné parent who is living on the Navajo reservation and has a child with an identified disability. This study will shed light on what practices and beliefs interact with my personal and social circumstances that may affect my family's response to the obstacles and stressors associated with the presence of my child's disability and definition of a disability. Additionally, findings from this research may contribute to the literature related to experiences of parents and other caregivers who have a child identified as having a disability. The research findings may improve future development of services provided for Diné families of children with a disability who live on the Navajo reservation by understanding and realizing the local Navajo need, local Navajo Knowledge, and local Navajo experience. In other words, this study is based on the premise that the success of educational and other intervention programs depends on the extent to which current experiences and perceptions of Diné families living on the Navajo reservation who have a child identified with a disability.

In participating in this study I agree to:

• Participate in a total of three interviews lasting no longer than an hour each. The first two of which will be face-to-face and the third by phone or in person which ever I should prefer.
• Be interviewed in a location I select.
• Be asked a series of questions from the semi-structured interview guide.
• Be audio recorded and my audio recordings will be transcribed.

I understand that:

• There are no anticipated risks involved in this study. However, answering questions about my child may cause me emotional distress. The study asks me to discuss my experiences of having a child with an identified disability which may cause emotional discomfort.
• Great consideration was given to the questions in the interview guide as to not embarrass or cause discomfort to me. In order to minimize the risk of distress, the principal investigator will share with me the content of the discussions when I first arrive.
• Participation is completely voluntary and if I choose to leave at any point I may.
• The possible benefits of this study to me are improvement of the education and other types of intervention programs for my child with a disability and my family.
• Any questions I have concerning my participation in this study will be answered by the principal investigator, Jocelyn Esquer, MA Early Childhood Special Education, 714-686-7790 or faculty advisor. Dr. Phil Ferguson, Chapman University, 714-744-7617.
• I may refuse to participate or may withdraw from this study at any time without any
• That no information that identifies me will be released without my separate consent and that all identifiable information will be protected to the limits allowed by law.
• If I am interested in the findings I can contact the principal investigator for information.
• I will receive no compensation for participating.
• I will be given a copy of this signed consent form
• If the study design or the use of the data is to be changed, I will be informed and my consent re-obtained.

I understand the information given to me. I am satisfied with the information given to me during the consent process and I have received answers to any questions I may have had about the research procedure.

To the best of my knowledge and belief, I have no physical or mental illness or difficulties that would increase the risk to me of participation in this study.

I understand that if I have any questions, comments, or concerns about the study or the informed consent process, I may write or call the Office of the Chancellor, Chapman University, One University Drive, Orange, CA 92866; Telephone (714) 997-6826.

I acknowledge that I have received a copy of this form and the Research Participant’s Bill of Rights.

I have read the above and understand it and hereby consent to the procedure(s) set forth.

Signature of Participant or Responsible Party ___________________________ Date ____________

Signature of Witness ___________________________

Signature of Principal Investigator ___________________________

APPROVED WINN 05/05/11
APPROVED FDICKSON 05/10/11

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INFORMED CONSENT (continued)

INFORMATION ABOUT:  
The Intersectionality of Race, Culture, and Disability within the Navajo Family  
CHAPMAN UNIVERSITY  
ONE UNIVERSITY DRIVE  
ORANGE, CA 92866

RESPONSIBLE INVESTIGATOR: Jocelyn Ann Esquer

Consent Agreement for Audio Recording

I have received an adequate description of the purpose and procedures for audio recording sessions during the course of the proposed research study. I give my consent to allow being audio recorded during participation in this study, and for those records to be reviewed by persons involved in the study, as well as for other professional purposes as described to me. I understand that all information will be kept confidential and will be reported in an anonymous fashion, and that the recordings will be destroyed as soon as they are fully transcribed. I further understand that I may withdraw this consent at any time without penalty.

Signature of Participant ________________________________ Date ________________

Signature of Witness ________________________________ Date ________________

Signature of Principal Investigator ________________________________ Date ________________

APPROVED  
FDICKSON 05/10/11  
APPROVED  
WINN 05/05/11
RESEARCH PARTICIPANT'S BILL OF RIGHTS

Any person who is requested to consent to participate as a subject in an experiment, or who is requested to consent on behalf of another, has the following rights:

1. To be told what the study is attempting to discover.

2. To be told what will happen in the study and whether any of the procedures, drugs or devices are different from what would be used in standard practice.

3. To be told about the risks, side effects or discomforts of the things that may happen to him/her.

4. To be told if he/she can expect any benefit from participating and, if so, what the benefits might be.

5. To be told what other choices he/she has and how they may be better or worse than being in the study.

6. To be allowed to ask any questions concerning the study both before agreeing to be involved and during the course of the study.

7. To be told what sort of medical treatment is available if any complications arise.

8. To refuse to participate at all before or after the study is started without any adverse effects.

9. To receive a copy of the signed and dated consent form.

10. To be free of pressures when considering whether he/she wishes to agree to be in the study.

If at any time you have questions regarding a research study, you should ask the researchers to answer them. You also may contact the Chapman University Institutional Review Board, which is concerned with the protection of volunteers in research projects. The Chapman University Institutional Review Board may be contacted either by telephoning the Office of Academic Affairs at (714) 997-6826 or by writing to the Chancellor, Office of Academic Affairs, Chapman University, One University Drive, Orange, CA 92866.
Interview Guide for Participants

Introduction

- The researcher with the participant(s)
- The general purpose of the study
- Purpose of the interview
- The ways in which the information will be used
- What will be expected of the participants
- Issues of anonymity
- Getting permission to record the interview
- Opening the interview

Part I: Background information

1. About the parent(s)
   - 1.1 address
   - 1.2 age
   - 1.3 gender
   - 1.4 occupation
   - 1.5 education
   - 1.6 religion
   - 1.7 family size
   - 1.8 experience of having other children with disability

2. About the child with disability
   - 2.1 age
   - 2.2 birth order of the child (if the child is the first or second, etc... in the family)
   - 2.3 onset of disability
   - 2.4 type of treatment (history)
   - 2.5 educational history
   - 2.6 other information

Part II: Parental ideas of disability

3. How can you best describe the situation of your child?
   - 3.1 What do you believe the condition of your child is?
   - 3.2 What do you think caused the condition of your child?
   - 3.3 How would you best explain/define disability?
   - 3.4 Tell me where you get this idea?
   - 3.5 What do you think are the possible causes of disability?

Part III: Parental ideas about the possibilities of improving their children’s condition
4. Do you think it is possible to improve the situation of your child?

4.1 How, in your opinion, is it possible to improve the situation of your child?
4.2 (If the response is impossible to improve situation) Can you explain why you think it is impossible to improve the situation?

5. Do you think you can do something to improve the situation of your child?

5.1 If not why do you think you cannot do anything?

Part IV: Parental ideas about learning potentials of the child

6. Do you believe that your child can learn like any other child?

6.1 In what way, do you think, it is possible to make the child learn?

7. Describe your child’s interaction in the family?
   7.1 Describe childcare in your family
   7.2 Who is available to help with childcare (family, relatives, friends, neighbors)?
   7.3 What are the number and different types of childcare jobs?
   7.4 How much of this childcare seems the result of having a child with a disability?
   7.5 How has having a child with a disability in the family affected your relationship with your other children?

8. Is he/she participating in home activities?

8.1 If yes, in what kinds of activities?
8.2 If not, describe why he/she is not participating?

Part V: Emotion-related experiences of parents

9. Which things bother you most regarding your child?

9.1 Why do you feel like that?
9.2 Which things bother you most about having your child?
9.3 What things make you worry related to your child?
9.4 What things are motivating you in your everyday caring of your child at home?

Part VI: Social/Cultural-related experiences of parent

10. How do you describe your social interactions with others?

10.1 Do you think your relationship with others is affected after you had your child?
10.2 How do you describe the reactions of family members, your neighbors, etc...to you or the situation of your child?
10.3 Do you get support from others (in the family, neighbors, community, organizations, etc...) relating to your child?
10.4 Do you think that your activities in your community are restricted as a result of having your child?
10.5 Describe some of the cultural influences on your family (television, games, organized sports, family cultural activities)?
10.6 Spiritual point of view?

11. Have you been out with your child?
   11.1 If not, why do you think you haven’t been out with your child?
   11.2 If yes, tell me your experiences.

12. Do you let your child play with other children?
   12.1 If yes, in which type of play activities, with whom?
   12.2 If not, tell me why you don’t let your child play with other children.
   12.3 How frequent is the participation in play groups?
   12.4 How structured? By whom were they set up?

**Part VII: Economic-related experiences of parents**

13. Do you think the presence of your child affects your economical situation?
   13.1 In what way do you think your economy is affected after you had your child?

**Part VIII: Parental expectations and wishes**

14. What are your expectations from your child?
15. What do you wish to get for your child?
16. What are you hoping relating to your child?

**Part IX: Parental involvement in school and intervention programs**

17. Do you have contact with your child’s school and or the teachers?
   17.1 Are participating in any of the school’s activities?
   17.2 If not, why are you not participating?
   17.3 How often do you meet teachers of your child?
   17.4 If not, why do you not meet them?

18. Tell me any other experiences you may have relating to your child.
PRE-APPLICATION ACTIVITIES

The Navajo Nation Human Research Review Board (NNHRRB) is authorized to use a twelve-phase review and approval process for all research protocols involving human subjects.

The twelve phases are:

Phase I: Community Partnership
Phase II: Tribal Program Partnership
Phase III: Screening of Research Application
Phase IV: NNHRRB Meeting Presentation
Phase V: Study Implementation
Phase VI: Data Findings
Phase VII: Data Work Session
Phase VIII: Final Report and Dissemination Plan
Phase IX: Transfer of Data
Phase X: Manuscript Publication
Phase XI: Community Feedback/Presentation
Phase XII: Transfer of Data to the Navajo Data Resource Center

LETTER OF INTENT

Any person interested in conducting human subject research shall inform the Navajo Nation Human Research Review Board of his/her intent by submitting a one page typewritten Letter of Intent to conduct research on the Navajo Nation by sending the letter to the following address:

Navajo Nation Human Research Review Board Support Office
Navajo Division of Health
P. O. Box 1390
Window Rock, Arizona 86515
Telephone Number: (928) 871-6650/6925
Fax Number: (928) 871-6259/6255

Upon receipt of The Letter of Intent by the Navajo Division of Health, the Navajo Nation shall be placed on notice that an individual desires to submit a Navajo Nation Human Research Review Board application. Upon receipt of the Letter of Intent, the staff assigned to the Navajo Nation Human Research Review Board shall immediately send out by electronic mail the NNHRRB Research Application and hard copies by regular mail serve the following attachments:

1. Navajo Nation Human Research Code
2. Navajo Nation Privacy and Access to Information Act
3. Schedule of NNHRRB Meetings and Deadline for Submission of Materials

The Letter of Intent shall initiate a pending file within the record keeping system established in the Navajo Division of Health. The individual submitting the Letter of Intent shall be designated
and referred to as the Principal Investigator or PI. The Principal Investigator is responsible for the overall implementation of the study.

**ABSTRACT**

The PI shall also submit a one or two page abstract with the following information:

1. The name of the proposed study,
2. A general description of the study population,
3. The geographical area where data will be collected,
4. The number of the subjects to be recruited for the study,
5. The gender of the subjects to be recruited for the study,
6. The proposed benefits to the subjects,
7. The proposed benefits to the Navajo Nation,
8. The proposed personal benefits to the Principal Investigator.
9. The proposed time period for the study to complete the twelve-phase process.

Upon receipt of the abstract, the Navajo Division of Health staff shall electronically send a copy of the Letter of Intent and Abstract to the Program Manager of the Navajo Historic Preservation Department of the Navajo Division of Natural Resources. The PI will be referred to the following address to obtain a permit, if necessary:

Navajo Historic Preservation Department  
P. O. Box 2898  
Window Rock, Arizona 86515  
Telephone Number: (928) 871-7132/7145

**TECHNICAL ASSISTANCE**

The assigned staff of the Navajo Division of Health shall provide telephone or office visit consultation to Principal Investigators in completing the NNHRRB Application.

Upon completion of the NNHRRB Application, one original and sixteen (16) copies shall be submitted to the Navajo Division of Health where it will be reviewed by assigned staff. There are fifteen (15) NNHRRB members and one staff reviewer. The original application is filed with the pending file and will not receive an assigned number until it has been approved by the NNHRRB.

If it is deemed complete, then it will be scheduled for the next regularly scheduled NNHRRB meeting. A copy of the proposed agenda shall be sent to the Principal Investigator confirming his presentation.
DESCRIPTION OF PHASES OF THE NNHRRB REVIEW AND APPROVAL PROCESS

The following section will describe the activities conducted during each phase of the twelve (12) phase review and approval process of the NNHRRB.

Phase I is known as the Community Partnership phase.
Depending upon where the Principal Investigator intends to conduct his study, the Principal Investigator will meet with the local community Navajo Nation chapters, school administrators, school boards, health facilities administrators, health advisory boards to obtain approving resolutions supporting the study.

Phase II is known as the Tribal Program Partnership phase.
This phase requires the Principal Investigator to engage one or two program administrators and the Division Director to obtain a letter of support for the study. The PI informs the administrators that the program shall receive the benefits of the preliminary and final analysis of the data collected. The Final Report containing the data shall be provided to the tribal program.

Phase III is the Screening of Research Application.
This phase includes the staff assigned by the Navajo Division of Health to review the contents of the NNHRRB Application submitted by the Principal Investigator. The staff shall notify the PI in writing by electronic mail the status of the application. Incomplete applications shall be placed in the pending status until all of the items required in the NNHRRB Application have been submitted. When an application is deemed complete, it will be placed on the agenda of the next regularly scheduled NNHRRB meeting. The NNHRRB shall have two-week review period prior to the meeting.

A copy of the agenda shall be sent to the PI by electronic mail. At the request of the PI, an agenda can be faxed. The agenda shall follow the format given below:

a. Continuation Request
b. Proposed Amendments to Protocols
c. Returning Presentations
d. Adverse Events
e. New Presentations
f. Manuscripts
g. Conference Abstracts

Phase IV is the NNHRRB Meeting Presentation.
All meetings are held in the Navajo Division of Health Conference Room. All meetings of the NNHRRB begin at 9:00 a.m. and conclude at 5:00 p.m. The Board has working lunch business meetings and will temporarily adjourn to conduct any board business at that time. All presenters shall be excused. The Board will return to its regular meeting after 1:00 p.m. to continue with its agenda.

Each Principal Investigator shall be allotted ten minutes to provide a summary of the highlights of the proposed study. Questions shall be posed by the NNHRRB and when it has completed its inquiry, the Board shall enter an executive session wherein the NNHRRB will deliberate and reach a decision. The Board will exit the executive session and return to the regular session of the meeting. The Principal Investigator shall return to the meeting and given the decision.
If the Board needs further documentation, materials and determines that the study shall need to be sent to an expert for further consultation, the Principal Investigator shall be informed to return to the next regularly scheduled meeting to receive the decision from both the consultant and the Board. This is called a "returning presentation". During the interim, the Principal Investigator shall be required to submit any other materials that the NNHRRB has requested.

**Phase V is the Study Implementation.**

Once a Principal Investigator has been given verbal approval, the PI must wait for one month to receive his/her Research Permit. The Permit is valid for one year and will expire on the date given in the letter of approval. The staff assigned by the Navajo Division of Health are responsible for composing the contents of the letter of approval with standard conditions and sending it to the Principal Investigator by fax and hard copy. The PI is expected to adhere to his proposed timeline provided in the study. The PI is required to reference the assigned research number for all inquiries whether by phone or letter. The PI can proceed with his study once he receives the Research Permit. The PI is required to adhere and comply with all of the standard conditions outlined in the Research Permit. Additional Specific Conditions may also be included in the Research Permit. Progress reports are submitted quarterly with one Annual Report per study year until all of the data has been collected.

Phase V is completed when the PI has finished his data collection activities as described in his/her timeline.

During this phase, the NNHRRB will receive proposed amendments and act upon them with the PI present.

If the study needs to continue beyond the approved time period, the PI shall submit a written letter sixty days in advance of the expiration by requesting for a continuation of his study. The Board will act upon this request with the PI present.

The PI may submit an abstract to NNHRRB for approval to present at a conference on his/her approved study. The NNHRRB recommends that conference abstracts be submitted only after one year of study has elapsed and that the same information has been presented locally prior to the request for a national or international presentation.

**Phase VI is the Data Analysis and Preliminary Findings Phase.**

The PI shall conduct data analysis and present any preliminary findings to the NNHRRB. During this phase, the Principal Investigator shall analyze the data and develop the preliminary findings into a presentation and provide the same to the NNHRRB during its regularly scheduled meeting.

**Phase VII is the Data Work Session.**

This data set is presented to the NNHRRB and a work session is scheduled with the partnering tribal program and other interested individuals including assigned staff of the Navajo Division of Health. The PI then reports back to the NNHRRB about the comments and results of the work session. The data report can then be amended or modified to include the unique interpretations offered by the program staff.

**Phase VIII is the Final Report and Submission of the Dissemination Plan.**

The Principal Investigator compiles a comprehensive report known as the Final Report and submits all of the products (materials, videos, photographs, etc.) to the NNHRRB. A Dissemination Plan containing dates, times and sites of where the Principal Investigator shall
provide final feedback regarding the results/outcome of the study will be submitted to the NNHRRB. The Board will approve the Final Report and Dissemination Plan with the PI present.

**Phase IX** is known as the Transfer of Data to the Navajo Nation. The PI and the NNHRRB determine the position and name of the Navajo Nation Program that will receive the data. The PI then submits the data to the program.

**Phase X** is known as the Manuscript Publication. This phase is optional. If the PI determines that he/she will develop the data into a proposed manuscript for publication, the PI as the first author will submit a completed manuscript in an approved publishable format. The PI/Author shall submit one original and sixteen copies of their proposed manuscript to the following address:

Navajo Nation Human Research Review Board  
Navajo Division of Health  
P. O. Box 1390  
Window Rock, AZ 86515

The assigned staff shall distribute the manuscripts to the NNHRRB with a cover sheet for comments and vote. The Cover Vote/Comment Sheet shall be returned to the assigned staff and tallied for voting purposes. All comments shall be forwarded to the PI to include in his revision of the manuscript. Upon revised manuscript submittal, the Board shall render a final vote. A vote of five approvals not including the chair shall determine a quorum vote and a letter of approval shall be sent to the PI/Author. A period of one month is given to the Board members to review proposed manuscripts. Upon approval by the Board, the PI/Author shall receive an approval letter with conditions.

Upon publication, the PI is requested to submit three copies of the publication to the Navajo Division of Health. One copy is filed, another is given to the partnering program and the other is reserved for the Navajo Nation Data Resource Center.

**Phase XI: Community Feedback and Presentation.** Utilizing the Dissemination Plan, the PI shall provide presentations to the chapters, schools, health boards, health facilities, tribal divisions and tribal programs regarding the data findings. Findings shall be presented to all officials and programs that provided initial support and approval.

**Phase XII: Transfer of Data to the Navajo Nation Data Resource Center.** Any data given to the Navajo Nation or the NNHRRB shall be given to the Navajo Nation Data Resource Center.
CHAPMAN UNIVERSITY INSTITUTIONAL REVIEW BOARD
NOTICE OF APPROVAL – RESEARCH WITH HUMAN PARTICIPANTS

PROJECT TITLE: Alternative Perspectives: Comparing Teacher Attitudes Toward Inclusion in 1913 and 2011

INVESTIGATORS: Jocelyn Esquer

ACADEMIC UNIT: College of Educational Studies

FUNDING AGENCY: N/A

APPROVAL DATE: 2/4/11

APPROVAL PERIOD: FROM: 2/4/11 TO: 2/4/11

RE-SUBMISSION DATE: 

APPROVAL CATEGORY: Exempt Continuation of IRB#0910H058 FOR RESEARCH INVOLVING HUMAN SUBJECTS:
The Institutional Review Board has reviewed the proposed use of human subjects in the project identified above and has determined that:

a) The rights and welfare of the subjects are adequately protected; the risks are outweighed by potential benefits; the informed consent of human subjects will be obtained by methods that are adequate and appropriate.

b) Type of Consent: WRITTEN: [X] ORAL: [ ] WAIVED: [ ]

c) Research involves use of: [ ] Minors [ ] Students [ ] Disabled
   [ ] Pregnant Women [ ] Patients [ ] Elderly
   [ ] Existing Records

PRINCIPAL INVESTIGATORS PLEASE NOTE:
1. All unanticipated adverse reactions encountered on any study must be reported in writing to the Institutional Review Board within 24 hours of their occurrence.
2. If significant modifications of this approved study are made, the Institutional Review Board must review them prior to initiation.
3. The principal investigator is responsible for retaining the original signed consent forms for 5 years after completion of the study.
4. All approved Informed Consent forms given to subjects must have the Institutional Review Board number and expiration date on the first page of the form and approval stamp on the first and last page of the form.

Signature: ____________________________
Dr. Fran C. Dickson, IRB Chair
**CHAPMAN UNIVERSITY INSTITUTIONAL REVIEW BOARD**

**CONTINUING REVIEW REQUEST / CLOSURE REPORT**

**Instructions:** Please complete all sections of this form and submit with attached documents, forms, and/or explanations to: Fran Dickson, CUIRB Chair, c/o Dept of Communication Studies, Chapman University, One University Drive, Orange, CA 92866.

<table>
<thead>
<tr>
<th>Principal Investigator (Last, First, M.I., Degree)</th>
<th>CUIRB Project Number</th>
<th>Date</th>
</tr>
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<tbody>
<tr>
<td>Esquer, Joselyn A</td>
<td>091014258</td>
<td>01/10/2011</td>
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**PROJECT TITLE:** ALTERNATIVE PERSPECTIVES: COMPARING TEACHER ATTITUDES TOWARD INCLUSION IN 1913 AND 2009 (2011)

1. a. Status of project: [X] Continuing, [ ] Completed (Closure), [ ] Terminated


   If no, is the research permanently closed to the enrollment of new subjects? [ ] Yes, [X] No.

   Have all subjects completed all research-related interventions? [X] Yes, [ ] No.

   Does the research remain active only for long-term follow-up of subjects? [X] Yes, [ ] No.

   Are the remaining research activities limited to data analysis? [X] Yes, [ ] No.

c. Are subjects being seen for follow-up? [X] Yes, [ ] No, [X] N/A.

d. Based on study results, has the risk/benefit ratio changed for this study? [ ] Yes, [X] No.

   If yes, explain:

   e. Has there been a change in the PI, or the PI's role in the study? [X] Yes, [ ] No.

   If yes, [X] No, if yes, explain:

   f. Has there been a change in the PI's duties at Chapman University? [X] Yes, [ ] No.

   If yes, explain:

   g. Have the physical or financial resources that are available to the study decreased since the last review? [X] Yes, [ ] No.

   If yes, explain:

   h. Has there been any change in research staff since the last review? [X] Yes, [ ] No.

   i. Do you wish to make any changes in research staff at this Continuing Review? [X] Yes, [ ] No.

   If yes, please indicate the type of change that you are requesting, the name of the individual(s) and the training and qualifications of the individual(s) as well as attach CUIRB Form "Request for Modification of Approved Project" with this submission.

**NOTE:** If an individual obtains informed consent independently of an investigator, they must have completed an approved training program, and documentation of this kept on file by the investigator.

2. Status of subjects

   a) Number of subjects enrolled in study since last report: [ ]

   [X] Since project began:

   b) Number of female subjects since last report:

   c) Number of minority subjects since last report:

   d) Number of subjects who signed consents but were dropped from study since last report ("screen failures"): [ ]

   e) Total number of patients who withdrew or were withdrawn from the study since last report.

   Summarize the reasons for withdrawal:

   f) Number of subjects considered part of a vulnerable population since last report:

   Indicate the reason subjects were considered part of a vulnerable population if a vulnerable population is being recruited:

   How do you continue to protect the vulnerable population?
g) Did all research subjects give written informed consent since last report? □ Yes □ No. ☒ N/A. If no, provide explanation: 

h) If no subjects have been enrolled in this study, have any additional risks been identified? □ Yes ☒ No

3. Serious Adverse Events and Unexpected Adverse Events
   a) Have there been any complications, untoward side effects, serious adverse events, or unexpected adverse events at this site since the last report? □ Yes. ☒ No
   b) If yes, have all events been reported? □ Yes. ☒ No
   c) Summarize all events which occurred: 
   d) Have any complications or untoward side effects been reported at other sites (SAE or IND Safety Reports) since last report? □ Yes. ☒ No. ☒ N/A. 
   e) If yes, have all non-local events been reported? □ Yes. □ No.

4. a) Have any modifications to the protocol (including sponsor amendments) been approved since the last review? □ Yes. ☒ No
   b) If yes, summarize the nature and purpose of all protocol modifications made since the time of last review:

5. a) Are you submitting any modifications to the protocol (including sponsor amendments) with this Continuing Review? □ Yes. ☒ No
   b) If yes, please summarize and include CUIRB Form "Request for Modification of Approved Project" with this submission

6. Have unanticipated risks or significant new findings been discovered since the last review that might affect the subject's willingness to continue participation? □ Yes. ☒ No.
   If yes, complete the following:
   a) Explain the risks or findings in detail: 
   b) Do these risks or findings require modification of the informed consent form? □ Yes □ No. If yes, have the modifications been submitted to the IRB? □ Yes □ No.
   c) Were subjects notified of these risks or findings? □ Yes □ No.
   d) Were subjects reconsented? □ Yes □ No

7. Did any unanticipated protocol deviations (including errors and accidents) occur since the last review? □ Yes. ☒ No. If yes, summarize all protocol deviations:

8. Advertising / Recruitment
   a) Were there any changes to the planned advertising or recruitment methods described in the original protocol since the last review? □ Yes. ☒ No. ☒ N/A.
   b) If yes, summarize all changes that occurred:

9. Provide a summary description of study progress, number enrolled, subject experiences, research results obtained thus far, any complaints about research, summary of subject benefits, any new scientific findings (or relevant recent literature available), and any new information since the CUIRB's last review. (Please attach a separate page) NOTE: This section must be completed.

10. Provide the original CUIRB approval date for this project: 01/2/2010
11. Do you wish to change the protocol or informed consent at this time?  
   Yes [x]  No [ ]  
   If yes, a CUIRB Form "Request for Modification of Approved Project"; clearly delineating the change, must be attached, along with copies of the old and new informed consent or protocol with changes clearly highlighted.

12. Since last reported, has there been any change in the financial interests of the Principal Investigator, any Co-investigator or their spouse or dependent child(ren) with respect to the sponsor or other entity external to Chapman whose business interests are related to the data or results of this project?  
   Yes [ ]  No [ ]  X/N/A (unfunded)  
   If "yes", describe in detail the change in financial interest. Use the space here or attach a separate sheet.

13. Has the Principal Investigator been an author or co-author on any published or submitted articles since the last continuing review of this project?  
   Yes [ ]  No [x]

14. Since last reported, has there been any change in the use of pharmacy, laboratory or radiology resources of the facility for procedures or tests that are not clinically indicated?  
   Yes [ ]  No [x]
   If yes, you must complete revised Impact Estimation Worksheets.

15. Since last report, have there been any changes to how information is stored?  
   Yes [ ]  No [x]
   If yes, please explain:

16. Have you had any external study monitor visits since the last review?  
   Yes [ ]  No [x]
   a. If yes, were there any serious findings or concerns identified by the monitor?  
      Yes [ ]  No [x]
      If so, please explain:
   b. If yes, please attach all Study Monitor Reports and Follow-up Memos with this Continuing Review submission

17. CERTIFICATION: By signing this document, I attest that all the information I have provided is accurate to the best of my knowledge. I certify that the rights and welfare of human subjects participating in this research project will be protected at all times and that the benefits to be gained from this study are commensurate with the risks involved. An approved informed consent will be properly executed in every case and documented in the medical record. I have reported all serious adverse events and unexpected adverse experiences as required. I will immediately report any complications arising from this study to the Chapman University Institutional Review Board (CUIRB). I certify that all investigators and all research staff who perform the informed consent procedure independently of an investigator have completed an approved educational program.

Principal Investigator:  
[Signature]  
[Date]

CUIRB Continuation/Completion Form Version Date: 11/2009
**CHAPMAN UNIVERSITY INSTITUTIONAL REVIEW BOARD**
**REQUEST FOR MODIFICATION OF APPROVED PROJECT**

**INSTRUCTIONS:** The entire form must be completed. Submit this application with the following:
- If the consent has been modified, submit a copy of the modified form with the changes marked, plus an unmarked copy for stamping.
- A copy of the modified research protocol
- A summary of protocol modifications

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<thead>
<tr>
<th>PRINCIPAL INVESTIGATOR (Last, First, M.I., Degree)</th>
<th>CUIRB PROJECT NUMBER</th>
<th>DATE</th>
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<tbody>
<tr>
<td>ESOVER, JASON A</td>
<td>07101058</td>
<td>01/10/2011</td>
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**PROJECT TITLE**
ALTERNATIVE PERSPECTIVES: COMPETING TEACHER ATTITUDES TOWARD INCLUSION IN 1973 AND 2009

1. **BRIEF DESCRIPTION OF ORIGINAL PROTOCOL:** Attach additional sheets as necessary

2. **DESCRIBE THE MODIFICATION(S) REQUESTED. INCLUDE REASONS FOR THE CHANGE(S).**

   PROJECT TITLE WILL BE CHANGED TO REFLECT CURRENT YEAR:
   
   ALTERNATIVE PERSPECTIVES: COMPETING TEACHER ATTITUDES TOWARD INCLUSION IN 1973 AND 2011

3. **WILL THE MODIFICATION(S), IN YOUR OPINION, INCREASE OR DECREASE THE RISK OF HARM TO THE SUBJECTS?**
   - [ ] Increase
   - [x] Decrease
   - [ ] No change

   Explain (Attach sheets as necessary):

4. **WILL THE MODIFICATION(S) ALTER THE APPROVED CONSENT FORM?**
   - [ ] Yes
   - [x] No

   If yes, attach original and one copy of a revised consent form, with additions and deletions clearly marked, to this form for review and approval.

5. **DID ANY UNANTICIPATED PROTOCOL DEVIATIONS (INCLUDING ERRORS AND ACCIDENTS) OCCUR SINCE THE LAST REVIEW?**
   - [ ] Yes
   - [x] No

   If yes, summarize all protocol deviations (Attach sheets as necessary):

6. **HAVE UNANTICIPATED RISKS OR SIGNIFICANT NEW FINDINGS BEEN DISCOVERED SINCE THE PREVIOUS CUIRB REVIEW THAT MIGHT AFFECT THE SUBJECTS' WILLINGNESS TO CONTINUE PARTICIPATION?**
   - [ ] Yes
   - [x] No

   If yes, complete the following:
   a) Explain the risks or findings in detail (Attached sheets as necessary):
   b) Do these risks or findings require modification of the informed consent form?  
      - [ ] Yes
      - [x] No
   c) Were subjects notified of these risks or findings?  
      - [ ] Yes
      - [ ] No
   d) Were subjects reconsented?  
      - [ ] Yes
      - [ ] No

I certify that none of these changes have been made and that no changes will be implemented prior to IRB review and approval.

---

Principal Investigator: [Signature]
Date: 01/10/2011

CUIRB Project Modification Request, 6/2001
The modification/amendment described on page 1 qualifies for and has been approved by expedited review.

The modification/amendment described on page 1 has been reviewed and approved by the Chapman University Institutional Review Board.

The modification/amendment described on page requires additional changes to secure approval.

COMMENTS:

APPROVED
EDICKSON 02/04/11

Chair, Chapman University Institutional Review Board

Date
Summary of Study Progress

January 12, 2011

Study Title:
Alternative Perspectives: Comparing Teacher Attitudes Toward Inclusion in 1913 and 2009

Study Progress:
The above titled study has yet to be approved by the Navajo Human Research Review Board. Therefore, the study has not begun, there are no enrolled participants, and data has not been collected. The researcher will re-submit all updated documentation to ensure that appropriate Tribal representative or group has issued approval, in writing, before proceeding with the online survey.

Attached is the original study proposal with relevant information and original application to the Chapman University Institutional Review Board.

Respectfully,

Jocelyn Esquer
CHAPMAN UNIVERSITY INSTITUTIONAL REVIEW BOARD
NOTICE OF APPROVAL – RESEARCH WITH HUMAN PARTICIPANTS

PROJECT TITLE: Alternative Perspectives: Comparing Teacher Attitudes Toward Inclusion in 1913 and 2009

INVESTIGATORS: Jocelyn Esquer

ACADEMIC UNIT: College of Educational Studies

FUNDING AGENCY: N/A

APPROVAL DATE: 1/12/10

APPROVAL PERIOD: FROM: 1/12/10 TO: 1/12/11

RE-SUBMISSION DATE:

APPROVAL CATEGORY: Exempt

FOR RESEARCH INVOLVING HUMAN SUBJECTS:
The Institutional Review Board has reviewed the proposed use of human subjects in the project identified above and has determined that:

a) The rights and welfare of the subjects are adequately protected; the risks are outweighed by potential benefits; the informed consent of human subjects will be obtained by methods that are adequate and appropriate.

b) Type of Consent: WRITTEN: [X] ORAL: [ ] WAIVED: [ ]

c) Research involves use of: [ ] Minors [ ] Students [ ] Disabled
[ ] Pregnant Women [ ] Patients [ ] Elderly
[ ] Existing Records

PRINCIPAL INVESTIGATORS PLEASE NOTE:
1. All unanticipated adverse reactions encountered on any study must be reported in writing to the Institutional Review Board within 24 hours of their occurrence.
2. If significant modifications of this approved study are made, the Institutional Review Board must review them prior to initiation.
3. The principal investigator is responsible for retaining the original signed consent forms for 5 years after completion of the study.
4. All approved Informed Consent forms given to subjects must have the Institutional Review Board number and expiration date on the first page of the form and approval stamp on the first and last page of the form.

APPROVED
DPORTER 01/12/10

Signature:______________________________
Dr. David Porter, CUIRB Chair
CHAPMAN UNIVERSITY INSTITUTIONAL REVIEW BOARD

APPLICATION TO INSTITUTIONAL REVIEW BOARD
for REVIEW and APPROVAL of
RESEARCH WITH HUMAN PARTICIPANTS

TITLE OF PROJECT: Alternative Perspectives...Comparing Teacher Attitudes Toward Inclusion in 1913 and 2009

DATE OF SUBMISSION: 11/24/2009

PROJECT TYPE: New: [X] Continuation [ ] CUIRB # _________ Other _________

PRINCIPAL INVESTIGATOR(S):
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FACULTY SPONSOR/CO-INVESTIGATOR:
If Student Project
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FUNDED: [X] No [ ] Yes Funding agency(ies); type of funding; grant number

PROJECT DURATION: (cannot exceed 1 year) 1 year

PROJECT DESCRIPTION: Attach separate page(s). A prepared study proposal (e.g., thesis; course project; independent study) may be attached in lieu of a description. The description must be sufficient to allow the CUIRB to achieve a clear understanding of the project objectives, methods, and significance.
For evaluation of your project, indicate by a [X] whether the following are involved:

- Patients as subjects
- Non-patient volunteers
- Students as subjects
- Trainees as subjects
- Minor subjects (less than 18 years)
- Subjects whose major language is not English
- Mentally disabled subjects
- Mentally retarded subjects
- Prisoners, parolees, or incarcerated subjects
- Subjects studied at non-Chapman locations
- Subjects studied at Chapman-affiliated hospitals
- Subjects in the Armed Services (active duty)
- Filming, video-, or voice-recording of subjects
- Department subject pool
- Pregnant women
- Data banks, data archives and/or registration records
- Subjects to be paid

THE PRINCIPAL INVESTIGATOR MUST ASSURE THE INSTITUTIONAL REVIEW BOARD THAT ALL PROCEDURES PERFORMED UNDER THE PROJECT WILL BE CONDUCTED BY INDIVIDUALS LEGALLY AND RESPONSIBLY ENTITLED TO DO SO, AND THAT ANY DEVIATION FROM THE PROJECT (E.G., CHANGE IN PRINCIPAL INVESTIGATORSHIP, RESEARCH METHODOLOGY, SUBJECT RECRUITMENT PROCEDURES, ETC.) WILL BE SUBMITTED TO THE CUIRB FOR ITS APPROVAL PRIOR TO ITS IMPLEMENTATION.

NOTE: Applications and any additional material requested by the CUIRB will not be processed unless legible, properly prepared, and signed personally by the Principal Investigator, Sponsor (if applicable), and the Principal Investigator’s supervisor or department/division chair.

I acknowledge that all procedures will meet relevant local, state, and federal regulations regarding the use of human subjects in research (CUIRB Institutional Assurance Concerning Human Research).

☐ I have completed the NIH Certification and included a copy with this proposal

☐ NIH Certificate currently on file in the office of the IRB Chair

Signature of Principal Investigator

Signature of Faculty Sponsor (if applicable)

For Office Use Only:

[ ] Full

[ ] Expedited

[ ] Exempt

Category #

Category #

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Alternative Perspectives . . . : Comparing Teacher Attitudes Toward Inclusion in 1913 and 2009

Summary/abstract:
Have teacher attitudes toward inclusion of students with disabilities changed significantly over the last 100 years? If so, how have these attitudes changed and how are those changes reflected? Results of a questionnaire completed will be aggregated to inform of perspectives toward inclusion on the Navajo reservation.

Proposal Description:

Description and Purpose

In 1913, a short article entitled “Backward Children and Forward Teachers” was published in The Training School Bulletin (A.J., 1913). Reflective of widespread societal perceptions of “backward” children during that time period, The Training School Bulletin was published by the administrators and researchers at the Training School at Vineland, New Jersey. It was here that researchers such as H. H. Goddard, E. A. Doll, and Alexander Johnson prepared much of their arguments for social policies that fit with their eugenic beliefs about the “burden of the feeble-minded” (Fernald, 1912). Responding to a number of special education classrooms being created in cities across the country, The Bulletin specifically targeted special education educators and asserted that self-contained classrooms and schools were the direction that such programs should take. The “Backward Children” article was no exception.

The “Backward Children” article reports finding from an informal survey of teachers, who were described as teachers “of long experience in the regular classes, who are at present, or recently have been, in charge of special classes” (Johnson, 1913, p. 97). Equally noteworthy, almost all of the participants in the survey had attended one of the annual “Summer Schools” training sessions at Vineland. In these early days of public school special education, the ‘summer schools’ (offered by a number of state institutions) were the only specialized training offered to those teaching these special needs students. The article includes the survey questions and reports on the results.

Despite a number of obvious methodological flaws, the study summarized in the article provides a fascinating snapshot of teacher attitudes about children with intellectual disabilities and where they should be educated. The focus of the survey is captured well by the first question: “What, if any, is the effect, beneficial or hurtful, on a backward or feeble-minded child, of contact with normal children in the class room?” (Johnson, 1913, p. 97). In short, through this and three subsequent questions, the survey asks teachers of the time what they believed about educating children with intellectual disabilities in general education classrooms. While it’s not feasible to replicate this study given some of the terminological and methodological differences existing today, I seek to determine how teacher attitudes regarding inclusion of students with disabilities on the Navajo reservation can be assessed in contemporary classrooms as well as draw comparisons to the findings form the original 1913 study.
Methodology

The four open-ended questions from the original questionnaire will be reworded to update any obsolete or offensive terminology (e.g., "feeble-minded children" will be changed to "children with intellectual and developmental disabilities"). The questions and instructions from the original questionnaire are provided at the end of this proposal. Following that, I have also included the revised questions. A set of five additional questions has been added. These are descriptive questions about the professional responsibilities and experiences of the respondent.

The project will use the internet-based program, Survey Monkey, to conduct an online survey. With knowledge and permission of district administrators, an e-mail message will be sent to all professional staff in primary and secondary educational institutions that exist on the Navajo reservation. This e-mail will contain a description of the project and contact information for further questions. In the body of the e-mail will be a link requesting educators to go to the Survey Monkey site and complete the questionnaire. All returned questionnaires will be anonymous. A reminder e-mail will be sent out 7 to 10 days after the first request. The teachers will not be told that the survey is a revised version of one done in 1913. The results will be collected and analyzed by myself, a doctoral student in disability studies under the supervision of my advising professor (Dr. Philip Ferguson). The answers will be compiled and analyzed using standard methods of content analysis for short-answer, open-ended questions. Basic descriptive statistics will be also compiled with frequency counts for the "yes/no" parts of the questionnaire. The guiding question for the study is: how do contemporary attitudes of teachers compare to those expressed by teachers almost a century earlier? Additionally, I will control for possible cultural differences between the teacher and students by including the ethnicity as a variable in the analysis. Given Navajo way of life, teachings and cultural perspectives on inclusion and respecting differences within community, it is possible that being a Navajo educator and/or student will influence the classroom dynamics in terms of inclusion and the unique needs of students. In short, I want to know how much or how little has changed in the beliefs of educators about the benefits of children with disabilities to be educated in inclusive settings.


1 Perhaps the most famous resident of Vineland was the woman Goddard called Deborah Kallikak. Goddard's book, The Kallikak Family, written as a case study of the dangers of allowing people identified as feeble-minded to reproduce, was published just one year earlier (Goddard, 1912).
Original Questionnaire from 1913 (Johnson, 1913, pp. 97-98) and Revised Questions:

1. What, if any, is the effect, beneficial or hurtful, on a backward or feeble-minded child, of contact with normal children in the classroom, in the following cases:
   a. If the child remains with normal children of his own physical age but of greater mental age?
   b. If the child is placed in a room with normal children of near his own mental age, but younger physical age?

2. What, if any, is the effect, beneficial or injurious, on the normal children under the above circumstances?

3. What is the general effect of mingling backward and defective children with normal children in the classroom or outside?

4. Are there any ill effects on the children or on their parents, of sending backward or defective children to the special classes?

   Please give your opinion based on experience in actual work. A brief statement of one or two illustrative cases will add to the values of the answers.

Revised Questionnaire

Please respond to the following questions based on your own experience as an educator.

1. What is the effect (either positive, negative or no impact), that you have observed regarding children with disabilities who have been placed in a general education classroom?

2. What is the effect (either positive, negative or no impact), that you have observed regarding non-disabled children who have been placed in general education classrooms with other children with disabilities?

3. What is the general effect of interaction between students with disabilities and nondisabled students both in the classroom and outside of the classroom?

4. Are there any observed negative effects -- on either the children and/or their parents -- when placing children with disabilities in special classrooms? Any observed positive effects?
The following additional questions will be asked:

5. Which of the following best describes your current position:
   a. ___ General Education Teacher
   b. ___ Special Education Teacher
   c. ___ Administrator
   d. ___ Specialist
   e. ___ Other (please specify)__________

6. How long have you been a professional educator:
   a. ___ Less than 5 years
   b. ___ From 5 to 10 years
   c. ___ From 10 to 15 years
   d. ___ More than 15 years

7. Which of the following best describes your current school:
   a. ___ A Navajo reservation public school (Arizona, Utah, New Mexico)
   b. ___ A Navajo reservation Bureau of Indian Affairs public school (Arizona, Utah, New Mexico)
   c. ___ A Navajo reservation private/charter/grant school (Arizona, Utah, New Mexico)
   d. ___ Other (please specify)________________________

8. What is the age range of the children with whom you spend most of your time?
   a. ___ 0-5 years of age
   b. ___ 6-11 years of age
   c. ___ 12-18 years of age
   d. ___ 13 and older
   e. ___ Multiple age groups

9. What is your ethnicity?
   a. ___ Navajo
   b. ___ Caucasian
   c. ___ Pacific Islander
   d. ___ Asian
   e. ___ African American
   f. ___ Other recognized North American Tribe
   g. ___ Hispanic
   h. ___ Other (please specify)__________

Thank you very much for your help.
[Date]

Dear Educator,

As a Ph.D. student from Chapman University’s College of Educational Studies I have developed a short survey that tries to shed light of the perceptions and experiences of special and general education teachers, and other education professionals, about their work with students with disabilities.

I am asking for your assistance in this important study by participating in an online survey which will take approximately 10-15 minutes and can be taken at any time convenient for you. If you agree to participate you may be assured that the results will be completely anonymous.

Your participation in this research is completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study your data will not be used.

The survey data will be protected by password protected computer files. Additionally, all hard copies of the surveys will be stored in a secure, locked filing cabinet in my office and destroyed after three years. Further, you may be assured that the researcher is not in any way affiliated with your school site or Department of Diné Education Navajo Nation. Results of the survey should be available in the Spring of 2010. If you would like results of the survey please feel free to contact me.

The survey uses the “Survey Monkey” web-based program and is a secure and reliable website for this project. To complete the survey, click on the link below and follow the directions:

[Hyperlink will be placed here]

If you have any questions or concerns regarding this survey, please contact Dr. Philip Ferguson at Chapman University (714-744-7617 or pferguson@chapman.edu) or myself (714-686-7790 or esque103@mail.chapman.edu). We appreciate your participation.

Thank you for your time and support.

Respectfully,

Jocelyn Esquer

PhD Student Disability Studies Emphasis