

MINUTES
Institutional Review Board
October 6, 2009

Present: Garrett Milam (Chair), Lisa Ferrari, Grace Kirchner, Mary Rose Lamb, David Lupher, and David Moore

The meeting was called to order at 8:15 a.m. Chair Milam reviewed the planned agenda for the meeting and also announced that the primary investigator of the first protocol to be reviewed would be present for part of the meeting.

PROTOCOL REVIEW

1. Protocol 0910-001

Chair Milam began the meeting explaining more about the background of this protocol which proposes to collect data among female participants. Milam noted that a very similar protocol was approved for data collection with males last year and that researchers addressed many of the concerns raised by last year's IRB committee (focusing primarily on privacy issues).

Board members expressed primary concerns about (1) whether there was a procedure in place to make referrals for individuals who, during the course of participating in this research, indicate need for psychological services and (2) what the researchers' plan would be should participants report incidents of on-going child abuse (or abuse of other vulnerable populations). A few additional concerns were discussed, including whether all of the homeless participants would be able to effectively redeem the Safeway gift card offered as compensation and whether the committee felt that the procedures in place to ensure security of the researchers and participants were adequate. Finally, further clarification was requested regarding the planned length of data storage, given that the protocol referred to storing data for "at least 5 years" and the consent form included a statement indicating that participant information would be stored for no longer than 5 years.

Several of these issues were discussed with the primary investigator (PI), who was present at the meeting, resulting in the following requested revisions and clarification in the protocol:

- 1) That some information regarding available psychological services at the be provided to participants who request such services.
- 2) That the PI and select members of the Committee determine any legal obligations for reporting suspected ongoing child abuse that participants may describe as part of their participation in the research study, along with the appropriate procedure for handling reported abuse. Additionally, the committee requested that the PI add clear statements in the consent form and in the experimenter script that informed participants of the need to report any

cases of current child abuse disclosed by participants, in order to inform them of this limit to confidentiality.

- 3) That appropriate guidelines, as well as corresponding language, be clarified and followed in regards to the issue of length of data storage. Milam indicated that he would check the guidelines around the duration of consent forms and survey data to ensure compliance with any ethical or legal requirements. The PI indicated that she used standard boilerplate language for the consent form but would be happy to make any changes as necessary to be in compliance with IRB and/or legal guidelines.

Action: The protocol was unanimously approved (6-0) provided that the issues described above were adequately addressed.

2. Protocol 0809-015

The floor was opened up for deliberation on this revised protocol, originally submitted the previous academic year, which proposes to investigate the effects of orthoses on gait patterns among children with Down's syndrome.

Primary issues discussed centered on the provision of the orthoses to participants, to ensure that the value of the orthoses was not high enough to constitute potential coercion of parents to allow their children's participation in the investigation. It was decided that the value of the orthotics is within the expected range of payments given to participants for 2 hours of their time (e.g., \$25) in many studies. The point was also raised that the study as proposed is noninvasive and the physical risks are relatively minor. The consensus was that the researchers adequately addressed the suggested revisions of the Committee.

Action: the committee unanimously approved the revised protocol (6-0).

OTHER ORDERS OF BUSINESS

Discussion of the University's Survey Policy

Milam talked briefly about the Survey policy regarding Institutional Research survey administration on campus. He noted that a university policy had been drafted, which he would distribute to committee members via email before the next meeting. Milam indicated that the committee has been charged to review this policy but suggested that this be tabled until the next meeting in November, in order to allow committee members to first read the policy.

New orders of business.

Milam raised one additional item for future discussion, namely whether the IRB should consider establishing a position on the use of Facebook (or similar social networking

sites) to recruit participants in research studies. It was noted that this issue potentially raises broader questions about the use of the internet in research (e.g., with Survey Monkey), particularly as this bears on privacy issues, when the use of the internet to conduct research invokes a “3rd party,” where data is stored on some external server rather than simply in a “locked file cabinet.” Another committee member noted that one issue with Survey Monkey that might be important for the committee to discuss is whether the use of data encryption should be required when using this (or a similar internet-based service), which is not the “default” option for such services.

The meeting was adjourned at 9:15 a.m.

Respectfully submitted,

David Moore