

Illinois Department of Children and Family Services  
**Institutional Review Board Meeting**  
**Minutes**  
**October 25, 2022**

**ON PHONE**

Janet Ahern  
Kathleen Anderson  
Tami Fuller  
Jennifer Eblen-Manning  
Wendi Ingersoll  
Brooke Taylor

**EXCUSED**

Dr. Margaret Scotellaro  
Robin LaSota

**CALL TO ORDER**

Janet Ahern called the meeting to order at 2:03 p.m. A quorum was present.

**APPROVAL OF MINUTES**

**MOTION:** Jennifer Eblen-Manning made a motion to approve the minutes September 27, 2022.

Tami Fuller seconded the motion and a unanimous vote from the remaining board members carried the motion.

**NEW PROPOSALS**

**David Ansong.** *Illinois DCFS Title IV-E Family First Prevention Services Act (FFPSA) Evaluation - Amendment.*

Adding \$25 gift card. Confidentiality would be maintained – but how would someone get a gift card? Gift cards cannot be given to state workers. No problems with the amendment.

Says that they are not going to have direct contact with families. Unclear as to who is doing what – and that should be clearer. Researcher is getting information from Chapin Hall -which is doing the Family First data collection. If Chapin Hall is getting the information from DCFS, they are not allowed to disclose the information to others. Steve Budde is the co-investigator (he works for Juvenile Protection Association).

Who is actually collecting the data? Who is doing the survey – is it Chapin Hall, JPA? Makes it sound like DCFS is sending out the invitation. Email the link to the survey and the EB providers are going to take it and the survey data will be taken via redcap and there is a consent form survey. There is a consent form at the beginning of the survey. If they take the survey, it goes to Chapin Hall – who will deidentify the information (without incentives) and then send the information to them. Is this correct?

Need UNC IRB approval on the survey.

Need more information on keeping the data collection confidential and secure.

Current Chapin Hall data sharing agreement expires in December 2022.

**MOTION:** Proposal will be tabled for researcher to respond to the questions raised by the board.

**James Chambliss.** *Ethical Considerations of Pregnancy in a Cognitively Delayed, Substance using 12-year-old.*

Child is from the central region – got her after her mother had been trafficking her. Involved in drug use with her mother. Kept running. Court sent her home to her mother, and she came back into care because of this issue. Became pregnant. Father was a 14-year-old boy. Huge runner – sent to a locked facility in Ohio and escaped within a day. Asked Dr. Naylor to keep her at K2 and asked her about decisions related to whether she would be keeping her child or not, despite the fact that she had limited pre-natal care. Went back to locked facility in Ohio and is currently still there (as last known).

Able to get the consent of the 12-year-old (who is now 13).

Missing the IRB from UIC.

No indication on her identity. Interesting research project. Not sure how instrumental it would be in educating the general public.

Not really a research project – a case study essentially. From a legal standpoint, 12 years old is pretty young to be signing a consent – defer to the Guardian’s Office regarding actual consent. Told Dr. Naylor that he had to go through IRB for protection.

What are the specific complexities that they want to share experience-wise with the broader medical community besides a huge expose of this child? What are the specifics that they want to share and how would it benefit? What is the implication to practice on a broader scale.

Very little information in the IRB submission about what they are trying to do/explore/what are the issues that they are exploring. Felt exploitative. Sent out a document with the girl’s name in it that shows a breach of confidentiality already.

DCFS has accepted single case studies for medical conditions. This child didn’t really spend that much time at K2. She is no longer at that facility.

We can ask the doctor to explain how it could be instructive and what the benefits are to this case.

How are they handling follow up medical?

Will invite the doctor to present at the next meeting.

**MOTION:** Proposal will be tabled for researcher to respond to the questions raised by the board.

**OTHER**

**Asthma Paper.** Best explanation on how screwed up DCFS’ medical records are. They are the best medical records.

Next meeting scheduled for November 22, 2022, at 2 PM.

The meeting adjourned at 2:51 pm.