# Illinois Department of Children and Family Services Institutional Review Board Meeting Minutes

January 25, 2022

**ON PHONE** Janet Ahern

Robin Albritton Christina Chojnacki Wendi Ingersoll Tami Fuller Kim Mann Robin LaSota

Dr. Margaret Scotellaro

Kelsey Julian Audrey Young Mary Clyde Pierce Brooke Taylor

## CALL TO ORDER

Janet Ahern called the meeting to order at 3:03 p.m. A quorum was present.

#### APPROVAL OF MINUTES

**MOTION:** Kim Mann made a motion to approve the minutes November 23, 2021.

Robin Albritton seconded the motion and a unanimous vote from the remaining board members carried the motion.

**MOTION:** Robin LaSota made a motion to approve the minutes January 5, 2022, once the changes were made to the approval status for Dana Weiner's research proposals.

Kim Man seconded the motion and a unanimous vote from the remaining board members carried the motion.

#### **FOLLOW UP**

<u>Mary Clyde Pierce.</u> The Epigenetic Impact of Abusive vs Accidental Head Trauma in Young Children: A PILOT Study.

Researchers attended the meeting to give more information regarding their research proposal. Working with diagnosing better and giving the children better outcomes.

Putting hard science behind young children to give them back their health and potential. Have a PILOT study and philanthropic backing to look into head injury and see how their brain is responding to that trauma. Looking at DNA to see what genes are turned on and which genes are turned off – to see what impact that has on the stress that the child is experiencing or the resiliency that the child is experiencing. Goal is to follow up with them to meet the families again and get another sample and possibly do more developmental things to see if they are on a good trajectory. Trying to diagnose at the beginning rather

than waiting for years to see if other problems show up. Enroll all children coming through Lurie with a head injury in this program.

Studies have shown that when children and being evaluated for abuse there is so much that is going on with that family, for them to go back in and re-evaluating, re-interviewing the family may contaminate the situation. So far, most families have agreed to the process.

This is a PILOT study, but really want to have the things in place, but show that they have the things in place so that when they get the protocol that it's working that they can go for bigger funding and programming.

Sampling of people that are being evaluated for abuse, felt that they were only going to have a slice and not the whole information on someone that has a head injury. Both groups have to agree to swabs. Being told that they are being collected for stress response and biology of how the child is responding to the trauma. Looking at the swabs and the saliva. So far, only 3 families have declined out of 28 families. Not asking for them to do anything cumbersome (they are doing it while they are in the ER).

Question raised as to whether it is made clear that providing the sample doesn't influence the way they are being investigated or cared for. They try to do training with the researchers as well. Let them know that they don't know what the results are yet – so it can't help or hinder. Make it clear to the families that they are learning. Let them know that it is not related to their clinical care at all. Let them know that it is staying within the research team only. Have not had anyone question that part so far. They identify themselves as different from the care providers. Careful to differentiate their roles. Make it clear and distinct and try to make that clear to families as well.

Concerns have been addressed by the researchers. Feel like it's a vulnerable time for people to be asked to do things. Potential for families to feel like they are being taken advantage of. What is the benefit to DCFS? She's getting to families prior to even DCFS getting involved in a situation.

Ultimately, the idea is to look at these biological markers that would reflect the environment that the child has been in prior to an injury and how that comes into play with the injury and recovery from the injury. Unsure how you can take out these biological factors with degree of head trauma. So much we don't know about severity of head trauma. If they are able to get that initial consent to families, if there is a denial from DCFS, then is there a hard stop in the study? Yes, that would be turned over to the guardian's office to give further consent.

The goal of the researchers is to have 200 families enrolled in this study overall. Why can't they get consent from all the parents – researcher indicated that the form is long. Suggestion is made to shorten the consent form. Why can't parents in both groups give consent to this study? Instead of waiving consent, get an updated consent from the guardian's office? Need consent from all the parents – unclear why they can't get consent at all aspects of the process. At the point where they are the parent, they give the consent. Assumption is being made that Lurie is doing their best to ensure that they are doing their best to get informed consent.

Will this really get a measurable result in that period of time?

If the researcher is willing to revise and get consent from all parties and resubmit the research proposal. IRB not willing to accept the rationale for the waiver.

**MOTION:** The research proposal is being denied. Brooke will let the researcher know that if they are willing to revise the research proposal and get consent from all parties that the board will reconsider the research proposal.

**Jamine Dettmering**. Effects of Validation on Responding during Escape Extinction.

Robin spoke with the researcher regarding the board's concerns and questions. The goal of this intervention is to help to complete behaviors that they typically seek to "escape". The intervention is tailored to the participant, and she indicates "If the participants have a single task they refuse, an ABAC design will be used (i.e. A=baseline, B=alternating treatments between extinction alone and extinction with supportive statements, A=baseline, C=extinction with supportive statements)."

Dr. Dettmering received IRB approval from her institution in June 2020 to conduct this minimal risk study which involves:

- 1. Collection of data from voice, video, digital, or image recordings made for research purposes.
- 2. Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies)

The researcher has specifications for maintaining confidentiality of the data and provides assurance of reporting being conducted "in such a way that no individual participant could be identified."

**MOTION:** Tami Fuller motioned to approve the proposal.

Dr. Margaret Scotellaro seconded the proposed motion and a unanimous vote from the remaining board members carried the motion.

#### **NEW PROPOSALS**

**Toleda Hart**. MYSI Human Growth & Sexual Avoidance Program.

The reseracher responded to the board's decision that at the time that she did not need to come through the IRB until she had youth in care as part of her study. She indicated that the SRAE workshops are provided to 6 youth in care who are placed in MYSI Group Homes ages ranging from 15-17 and would that make a difference.

With that information, the board indicated that they would re-review the research proposal with the new information that had been received.

Youth have a right to know and get treatment and have a right to make decisions.

**MOTION:** This research proposal is being denied due to the structure of the intervention seems to imply limitations that would adversely impact the Department's commitment to diversity, equity and inclusion.

**Jallah Wilson**. Turnover and Youth Outcomes.

Researcher responded to board's concerns and questions. She is doing the research only for her master's program and the information and data that she is gathering will not be published. She does not plan to record the interviews, but will take notes and the notes will be stored in a word document on her laptop with all identifying information removed from the notes.

She does not have access to SACWIS, but will extend the offer to participate in her study to other caseworkers who are not on her current supervisor's team, but only to those in her same office that she interacts with on a regular basis.

**MOTION:** Tami Fuller motioned to approve the proposal.

Robin LaSota seconded the proposed motion and a unanimous vote from the remaining board members carried the motion.

## **NEW PROPOSALS:**

**Tamara Fuller**. Evaluation of the Youth Advocate Program.

Department asked if they could stop evaluation the Community Conscious Network and start evaluating a new program for dually involved youth (the youth advocate program). Using same methodology that was used for CCN evaluation to be appropriate for the YAP program.

Doing a survey for the youth who are receiving services and the family and the youth advocates. It's an online survey that they get about 3 months after they are enrolled in the program. Look at outcomes of the youth involved in the program (like permanency, placement stability, safety and substitute care). Have access to the data already.

Applied for UIUC IRB approval simultaneously. CCN evaluation was ruled as exempt because the university does not see it the same as research. Assumption is that it will be ruled as exempt as well - as it is strictly an internal evaluation.

Suggestion made to soften the consent language. "While you may not benefit directly from the study, your participation in the study provides an opportunity to share your views about the Youth Advocate Program. The information you provide may help improve the program for youth similar to yourself."

**MOTION:** Robin LaSota motioned to approve the proposal.

Christina Chojnacki seconded the proposed motion, Tami Fuller abstained from the vote, and a unanimous vote from the remaining board members carried the motion.

<u>Nidia Ruedas-Gracia</u>. Illinois Foster Youth's Pathways to Community College Completion.

If they want us to give them lists of youth enrolled in colleges, that would be how DCFS would be involved. Might be looking to see if school can identify youth for waivers. Unsure exactly who the letter requesting assistance goes to.

Sounds like a really good study. Talk to youth about their barriers and supports. Questions were good. Nothing that is really needed from DCFS except for names.

**MOTION:** Tami Fuller motioned to approve the proposal.

Christina Chojnacki seconded the proposed motion and a unanimous vote from the remaining board members carried the motion.

## **OTHER:**

Introduction of new board member from Operations. Welcomed Wendi Ingersoll to the board.

**Introduction of new board member from Quality Assurance**. Welcomed Jennifer Eblen-Manning to the board.

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

The meeting adjourned at 4:25 pm.