

Illinois Department of Children and Family Services
Institutional Review Board Meeting
Minutes
January 24, 2023

ON VIDEO

David Fox
Janet Ahern
Kathleen Anderson
Dr. Margaret Scotellaro
Robin LaSota
Jennifer Eblen-Manning
Tami Fuller
Brooke Taylor

EXCUSED

Wendi Ingersoll

CALL TO ORDER

Janet Ahern called the meeting to order at 2:02 p.m. A quorum was present.

APPROVAL OF MINUTES

MOTION: Jennifer Eblen-Manning made a motion to approve the minutes November 22, 2022.

Janet Ahern seconded the motion and a unanimous vote from the remaining board members carried the motion.

FOLLOW UP

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

Collaborate and share with cases so others can benefit from the knowledge.

Exceptional case that you don't see very often. From an educational standpoint, very rewarding. Had a privilege of working with her. Details that she is 12, substance use, STDs, all the factors that played into informed decision so that she could make the best decisions that she could. Helpful thing that cases like this that actually do exist and to make others aware of.

Other information that will be used besides case history – nothing that could personally identify the individual. She did not have someone who could take care of her and here she is getting ready to have a child. Things to be aware of that things like this can happen. In the medical community, create guidelines and protocol – basically information about outstanding factors that are involved in this case.

Does he think that she understood the consent that she signed? That is a good question. 1500 words maximum, all highlighting the different ethical concepts that come up in a case like this. Would they be discussing whether she would be keeping her child. What defines decision making capacity. Fact that her functional IQ registered pretty low – is that accurate? Unknown. Details are going to be presented in that regards to present that situations like this do exist.

Literally don't know who else would read the paper other than those in academia. This is something that people should be aware does exist and have some kind of thought about in case they run into a similar situation.

Publication source? At UIC there is an ethics essay contest. Submitting this to the ethics committee. He hasn't written it yet because he's been waiting to get approval to do so. It will make more sense as he starts writing it and doing the research that led to decision making capacity and not so much the details himself. Unknown what will become of it himself.

Different medical issues to consider. All the things that factor into the case are the topics that are planned to be talked about. A lot is really going to be around background research what's out there. Not information to describe her. It might be published, Dr. Naylor feels like it's a really strong case since it's such a different case.

Took a while to figure out what they wanted to do with her when she was admitted into K2. Able to consent to medical care while pregnant, but once she has the baby, she no longer has the capacity to give consent.

Is there a conclusion that is going to be drawn, or some experience that is going to be provided? Only real guidance/advice – try to provide the best education possible around all the pieces. Trying to educate the individual around what their STDs were and how they can affect the fetus; education around having a baby; etc. – all things that the child did not understand. Understanding a child that is presenting with adult symptoms and yet is still a child.

Educational benefit to share with others.

Would want to see the finished product. Unable to discern what the educational benefit would be other than an interesting story. Appears that it's not yet been formulated. Unclear as to how it's going to be beneficial to others. Would like to see exactly what information would be sharing. Worried that there aren't a lot of pregnant 12-year-olds in DCFS custody, so may be easy to discern who that individual is. Lot of questions and this youth is the definition of a vulnerable subject.

Ask that we see the article before it's submitted to any publications. Might be some real good things about what is done in terms of counseling a 12-year-old on what she's done to her unborn child and what it means to be 12-years-old and giving birth.

Would like to see it before it is presented to the ethics committee. If he submits it, and it wins – there is a potential for it to be shared more widely.

MOTION: Margaret Scotellaro motioned to approve the proposal with the caveat to allow the board to review the manuscript prior to giving full IRB approval.

Jennifer Eblen-Manning seconded the proposed motion and a unanimous vote from the remaining board members carried the motion.

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

Sent the information regarding gift cards to the ethics officer – who sent the rule along regarding the gift ban. Clear that DCFS employees cannot accept a gift card; however when asked about private agency personnel – he could not speak to that but stated that it is up to their agency and/or ethics board.

Think that the survey is important. If there is an incentive out there, there is more response. The fact that this is federal legislation and Family First – and that DCFS is supporting this – the survey would be useful in how to proceed with implementation to make the effort more successful. Better to offer the incentive – more chance of people willing to give 20-25 minutes to complete it. May only get 33-40% response rate.

Where is the money coming from? Is it coming from DCFS – does it appear that we are paying to incentivize responses. Concern from a legal standpoint – we do not want there to be a trace back to DCFS regarding the monetary compensation.

Consensus regarding the \$25 gift card incentive is that if it is not a violation, most are okay with it.

Questions regarding the data they are collecting – are they only asking to use our data, but not data that is being collected from other agencies. This is just a survey for the amendment, and they are using administrative data for other aspects of the evaluation, but the amendment is only a survey. If the administrative data contains data from other agencies, we can only agree to the use of our data.

MOTION: Robin LaSota motioned to approve the proposal.

Jennifer Eblen-Manning seconded the proposed motion and a unanimous vote from the remaining board members carried the motion.

NEW PROPOSALS

Amy Dworsky. *DCFS LifeSet Evaluation Phase II.*

No consent issues – as they are all over 18. Looking now to link with employment information from Illinois Department of Employment Security. Following the same procedure for security that they utilized with the student clearinghouse. Looking at employment/education outcomes.

No problem with talking to the youth. Hoping that they get some results. Not looking to get consent from the youth.

MOTION: Robin LaSota motioned to approve the proposal.

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

OTHER

Request for access to CFSR Contextual Data Profiles. All aggregate data. Nothing identifying in there.

Next meeting scheduled for February 28, 2023, at 2 PM.

The meeting adjourned at 3:16 pm.