SB 198

Thank you Madame Chair my name is Serene Rose O'Hara-Jolley and I live in Fairbanks, I am an adjunct professor at University of Alaska Fairbanks and I am here representing myself.

I am here to voice my concerns with SB 198 and urge the committee to vote to amend. In graduate school I had the privilege of gaining IRB approval. I would like to speak to the IRB process as I have some concerns I hope the committee will take into consideration. The IRB does in fact have stringent ethical standards and all research that is approved by the board must pass rigorous guidelines. However, in the past, all though unintentional the IRB has approved studies that have harmed vulnerable population, and although they have learned from these missteps and taken steps to prevent these oversights from happening again we must remember they are not infallible. We must insure that the IRB is considering all aspects of the potential risk to the health and safety of participants. The IRB only applies their guidelines to the research proposal as it is laid before the board. Aspects that may need to be ethically considered, if not directly laid out in the study, fall out side of the potential purview of the board. To put that in the context of the current study. Right now, the study as written is concerned with the insertion of LARC and its effects on pregnancy rates, currently it layouts no provisions or funding for the removal of LARC. If this is not explicitly part of the study the IRB could potentially not address removal. I personally have reservations about implanting and inserting medical devises that require not only an additional doctors visit but the funds to pay for removal or access to insurance that covers it. LARC removal is expensive and will eventually be necessary for all participants as all LARC has an expiration date. Since this proposal as written does not account for this it potentially leaves an already at risk group of women with another financial responsibility, one that could lead to adverse heath effects if the LARC is not removed when needed. In testimony on Tuesday in front of this committee the PI stated that they would help women to gain insurance to cover costs, however if a participants is not able to obtain insurance one adverse effect could either use all the financial resources of the study or the study could leave that woman to bare the burden of that cost. In addition, retention rates of all participants in studies are small and no provisions are in place if a women leaves Alaska for the removal of the device. I also have concerns that will be addressed by the IRB but I think should also be brought to the attention of the committee as the state is funding this project. This study is potentially coercive if participants financially feel as though they have no other option. In addition, asking women who have just given birth and are potentially not of sound mind from chemical substances self administered or administered by hospital staff calls into question for me personally the ethics of this study. It does not seem that these women will be in a position to give informed consent. We already know that LARC prevents untended pregnancies, we do not need to put a group of women at risk to study something we already know to be fact. I urge the committee to make sure that our state is funding a project that is safe for the women involved and not setting them up for further financial hardship or medical complications. I urge the committee to amend the proposal to address these concerns so that the state does not fund a project that potentially harms women.

Thank you for your time