**Commonwealth of Massachusetts**

**Department of Developmental Services**

**Research Review Committee Meeting Minutes**

Date: September 1, 2023

By Teams: Erin Brown (Chairperson), Kathleen Gallagher, Patricia Shook, Deborah Dreyfus, Rosalie Edes, Joshua Greenberg, and Freddy Torbey (observer/minutes)

Additional Attendees: Sofia Langman

**Agenda Items**

1. Administrative matters.
2. “Practical Functional Assessment and Skills-Based Treatment with Adults with Intellectual Disabilities,” Dr. Cory Whelan
3. “User study of a self care app prototype specifically designed for people with intellectual and developmental disabilities (I/DD),” Drs. Krishna Venkatasubramanian & Tina-Marie Ranalli

## HOUSEKEEPING

* Chair established quorum
* Chair discussed quorum and noted the absence of Joseph Weru and Janet George, as well as introducing Sofia Langman
* Chair presented proposals for discussion

### Review and Vote on July 7, 2023, Meeting Minutes

Outcome

* Chair moved for a vote and Committee members unanimously agreed to adopt the July 7, 2023, meeting minutes (Rosalie Edes abstained due to absence)

**“Practical Functional Assessment and Skills-Based Treatment with Adults with Intellectual Disabilities,”**

**Dr. Cory Whelan**

Discussion

* RRC discussed previous meeting’s inquiries and requests to Dr. Whelan, and Dr. Whelan’s response to concerns raised
* RRC discussed possibility of physical harm being inflicted by individuals on themselves when subjected to the conditions the proposal is meant to research
* RRC discussed how comfortability and expression of harm or discomfort of individuals will be gaged considering their limited expressive abilities
* RRC discussed determination of competency for participation in study, and the possibility of assuming consent for participation or requiring consent from another legally authorized person
* RRC discussed adequateness of proposed measures to lessen or end psychological distress experienced by individuals during the study

Issues

* Amended proposal suggests protecting individuals’ privacy rights by ensuring ignorance of research being conducted by quotidian care providers, while also suggesting that care providers will know of the study
* Amended proposal does not address the longevity of data retention access for Dr. Whelan as well as anyone who might replace Dr. Whelan in his position at Vinfen
* Proposal does not clarify subject’s physical setting and ensuring privacy of individuals who are not participating in the study

Outcome

* Chair moved, and RRC members agreed, to approve proposed study on condition of adequate reassurances regarding ensuring individuals’ physical and psychological well-being; clarification regarding the protection of privacy rights of individuals not involved in the study; as well as the longevity of data retention access to Dr. Whelan and anyone who might otherwise replace him

### CONDITIONALLY APPROVED RESEARCH

**“Practical Functional Assessment and Skills-Based Treatment with Adults with Intellectual Disabilities,”**

**Dr. Cory Whelan**

### NON-APPROVED RESEARCH

None

### CLOSING MATTERS

None