This presentation will specifically discuss research involving people with disabilities and how those serving on Institutional Review Boards (IRB) need to expand their understanding of this population when it comes to research participation and language used with participants.

The Belmont Report (1979) provides the three guiding ethical principles for conducting research: (1) respect for persons, which includes autonomy, (2) beneficence, and (3) justice. These should be applied to all populations and understandably there should be stricter regulations when dealing with marginalized populations but these “restrictions” need to be made with understanding about these populations.

An Institutional Review Board (IRB) allowed abuse-related researchers to recruit and screen prospective participants without disabilities via email, but then denied email recruitment to occur for participants with disabilities. If it is allowed for participants without disabilities, then it should be allowed for participants with disabilities as well, especially when this method of communication is the best or only possible means of initial communication for certain disabilities (e.g., Autism Spectrum Disorder). This restriction can result in discrimination, skewed data, and further marginalization of this population. Additionally, it compromises their autonomy by removing the choice of participating in research. The ethical principle of justice is violated as there is an unfair distribution in types of research participant as well as the benefits stemming from research findings. For example, when women with disabilities are not included in abuse-related research, the unique types of abuse they experience are not captured on abuse screening tools developed, domestic violence shelters cannot accommodate their needs, and policies are created leaving out protections for them.

Interview Question: Does level of connection with your service dog impact leisure choice? i.e. did you participate in different or more ambitious forms of leisure because you felt safer or more connected with another service animal?

This question implies that people with disabilities can only have relationships with animals and not other humans.

Rewording suggestion:
• “Does having a service dog affect your leisure choice? i.e., did you participate in different or more ambitious forms of leisure because you felt safer or more empowered with a service dog?”

Thank you to the following for all the support:
• Teaching Responsible Conduct of Research Cohort
• SFA Office of Research and Sponsored Programs
• SFA Dept. of Kinesiology & Health Science
• Those willing to share their IRB experiences