



Expanding Our Understanding of People with Disabilities in Research



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Introduction

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.

Purpose

To bring attention to the decisions made by Institutional Review Boards (IRB) on research involving people with disabilities and the implications of those decisions.

Discriminatory Language: Case Study

IRB members should be aware of the type of language used with participants. Most language used in research is ableist, which discriminates against people with disabilities. For example, an interview question approved by an IRB but found offensive to some of the interview participants with disabilities, “Does level of connection with your service animal impact leisure choice?” People with disabilities thought this question implied that people with disabilities can only have relationships with animals and not other people.

Abuse-Related Research: Case Study

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?)”

Implications

- (1) Respect for Persons, including autonomy
 - Can compromise autonomy by removing the choice of participating in research because a specific recruitment method is not allowed
- (2) Beneficence
 - Language usage is discriminatory
- (3) Justice
 - An unfair distribution in types of research participant as well as the benefits stemming from research findings
 - Disability-related types of abuse are not captured on abuse screening tools developed, domestic violence shelters cannot accommodate their needs, and policies are created leaving out protections for them.

Conclusion & Recommendations

- IRB members need to expand their understanding about specific populations in order to avoid further marginalizing them, such as people with disabilities.
- One suggestion is to have a member of the population provide training about working with their population to the IRB members to raise awareness of issues that may be offensive or result in further marginalization.
- Further research in this area is needed in the future to ensure all members of society are accurately represented, treated fairly and respectfully, and benefit from the research being produced.

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