

2021 Directors Retreat Session 2 Roundtable

Notes

Name of Roundtable: Equity in Research Activities

Facilitator: Rodney Samaco

Staff Support: Dana Kim

Major Themes Discussed:

General lack of equity in research activities

- IRB process (i.e. difficult to get consent form in plain language)
 - Categorizing accessibility needs by those with disability
 - Speaking in medical model of disability to have accessibility
 - Lack of training for navigating this issue
- Non-well-versed researchers not as well accepted by peers/colleagues
 - Dismissive of their opinion and perspective

Different facets of “accessibility” (from opening presentation)

- Can use different strategies to address these issues
 - One size does not fit all for an experiment or across disciplines
 - How to include all stakeholders and participants?
 - Methods, recruitment, etc.
 - Lack of training for accessible communication and dissemination
 - Need education to combat this, maybe responsibility falls on those who are already know about the issue and have experience/strategies navigating it
 - Need change of existing laws; policies meant as protections have instead become roadblocks for IDD research
 - NOT just about changing study but making it more accessible
 - Want to see a legal, advocacy expert coming in to discuss/enact change in this issue too

Inclusivity

- Should involve and collaborate with those with lived experience; get feedback about the research project and give them credit for their contributions
 - Nonscientists being included in the research process. There is some concern about a negative reaction, but no one in discussion had experienced this
 - Need to provide support for disability community to be involved in the research activities
 - Encourage speaking up in these issues
 - Bringing together different groups and leaders to address these issues to create change

Considering the terms used around equity and their accessibility to those in scientific research

- For example, intersectionality can be a foreign term to someone working in chemistry lab
 - Diversity includes several factors and lab/bench scientists are often not well-versed in this
 - Should be included in all research activities

Accountability

- Community should be holding itself accountable to learn these things. Need to observe and notice power dynamics and bring these topics up as directors
 - Equity tourism (performative equity). Are we just checking off a DEI box?

- Is IRB issue discussed a low hanging fruit in this issue?
- Many discussions of diversity often does not truly include disability
- Balancing “confronting” vs. encouraging
- Should be talking explicitly about who is involved in what (i.e. their race, gender, or lack of overall diversity among people who are making decisions)
- Incremental change, start early in training level, create space for this and ask questions, here to learn

Support Needed:

- Need bridge to gap between disability community and researchers.
 - Ex. Making sure they have tools to understand research language and intent

Other Action Items:

- Hold ourselves/each other accountable, be careful not to fall into trap of equity tourism
- Be proactive to address this issue, e.g., involving everyone, creating space for discussion, asking questions