Pushing Past Pedagogy: Improving Inclusivity in Research

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# Abstract

This paper suggests several areas of current research practices that need to be examined with a critical lens. We as assistive and accessibility technology researchers; with clinical training; and advocates of neurodiversity add our voices to the merging of critical disability studies within the HCI community. We expect the workshop to provide reflective discussion on the past, present, and future of CHI as it relates to the inclusion and equity for disabled participants, students, and scholars. We contribute current and historic aspects of research practice from our clinical research specialties that limit this equity. We hope to learn from the workshop members and work together to devise ways to remedy these disparities in research practice.

# Author Keywords

Research ethics; inclusivity; diversity, justice

# Ethical Principles in Human Subjects Research

**Respect for Persons:** Participants are treated as autonomous agents and persons with diminished autonomy are entitled to protection.

**Beneficence:**  Balancing risk and benefits to ensure that benefit is maximized and harm minimized to the extent possible.

**Justice:** Participants are treated equitably with a fair distribution of benefits and burdens as appropriate. An injustice occurs when an entitled benefit is denied without good reason or when some undue burden is imposed.



# CSS Concepts

• **Human-centered computing~Human computer interaction (HCI)**

# Introduction

Conference organizers have rightly revitalized the topic of inclusivity in research as institutional and pedagogical barriers have limited the participation of disabled people in research as participants and as disabled scholars generating and exploring research questions in their fields of inquiry. A critical first step in improving inclusivity and equity is to identify tenets and pillars of accepted knowledge in research and demonstrate how they actually serve as a means of excluding disabled people from participation. The following mainstream principles can be questioned as myths and not necessary to conducting ethical research. In fact, these supposed pillars of accepted knowledge can sabotage foundational research principles such as beneficence, respect for persons and justice.

Beneficence is the term we have adopted as part of the code of conduct in human subject research required since the inception of the Belmont Report in the United States [1]. The Belmont Report argues that investigators and institutions should conduct research that is likely to substantially benefit the public and the participant and balance risks and benefits [5]. However, the expectation of public benefit is not required to conduct ethical research and individual concerns and benefit are paramount. Respect for Persons maintains participants should be respected as autonomous and that vulnerable participants should be afforded protection [4]. The third basic principle of Justice requires people are treated equitably with a fair distribution of benefits and burdens [4].

We find that these ethical principles in human subjects research have transitioned to an institutional pedagogy in which assumptions are made regarding best practice in scientific methodology. In this workshop, we would like to discuss the following list of assumptions and consider alternatives to improve justice and beneficence for disabled participants as well as increase equity for disabled participants, students, and scholars. We challenge the mainstream notions that:

* Clinical groups need to be homogeneous.
* Single case designs are less rigorous than group studies.
* Experimental clinical studies need control groups.
* Quantitative data is valued over qualitative data.
* Data reliability needs to be confirmed from an outside source.
* Studies need to occur in controlled laboratory settings.
* Variability is undesirable.
* Outliers are excluded.
* Consent to participate has to be verbal
* Individuals with significant disabilities who cannot read are unable to consent for themselves.
* Western philosophy takes precedence over Eastern

We have also taken issue with the trend that:

* People without families or natural allies are disadvantaged
* Institutional Review Boards with members without disabilities make decisions for those with disabilities.

# Methods

To prepare for further discusion at the workshop, we have organized these practices into themes: research design and theory; statistical analysis approaches; reliability and validity; and institutional and participation-level factors.

## Design and Theory

This refers to research designs that are rated in a hierarchal manner in terms of quality with randomized control trials (RCTs) rated as the highest quality followed by controlled trials without randomization, cohort or case-control study, multiple time series or dramatic results from uncontrolled experiments, opinions of respected authorities, descriptive studies/case reports, and reports of expert committees [7]. This hierarchy makes several assumptions. First, inclusion of a clinical and control group is the “optimal” design. Further, clinical groups should be as homogeneous as possible to generalize results, and single case designs are less preferred. However, these premises conflict with ethical research principles of respect for persons and justice. Respect for persons assumes that individuals are autonomous, unique and have the capacity for self-governance. The reality of grouping in a homogeneous fashion relinquishes that very autonomy. Also, it is assumed that experimental studies with clinical populations require a control group also referred to as neurotypical, typical, and normal. This violates the principle of Justice which requires equitable treatment of individuals, not a comparison to normal.

## Statistical Analysis

Statistical methods are application of mathematical formulas and other analyses to convert raw numerical data to reach conclusions regarding the research questions. In this entire paradigm, numbers and other quantitative data are valued over qualitative data creating an intrinsic bias that all important behavior should be able to be numerically measured. However, research questions utilizing qualitative methodologies are well-suited to relating people’s experiences of a condition and factors related to receiving an intervention [2]. These methodologies and analyses have their own rigor, and they are perhaps more equitable and demonstrate respect for persons compared to quantitative analyses. Other statistical principles also prevent inclusivity such as removing outliers from analyses and viewing variability in data as unreliable or suspect [6].

## Reliability and Validity

Reliability and validity are two constructs that serve to improve the rigor or quality of the research [3]. These constructs can serve to reduce inclusivity and diversity in research. The concept of reliability infers that some outside source needs to confirm the accuracy of the results. This is challenging for individuals who do not share the experience of the disabled participant or disabled scholar. Who is to say that a disabled person engaging in a specific behavior (e.g. pushing a test item away) is indicating protest? Perhaps, the person wanted to move the item into a different viewing angle or a host of other possibilities. The entire concept of reliability of data can deny a disabled person their experience to be interpreted individually.

Validity, which refers to the truth or soundness of the data, can also be a barrier to inclusion. For example, the idea that studies should be conducted in a controlled laboratory setting to improve rigor creates challenges for individuals that have limited mobility and cannot travel to these settings. Additionally, a laboratory setting removes much of the context in which human experience occurs, rendering the results suspicious in many cases. How the stripped-down behavior of a disabled participant in a lab setting is interpreted outside of their daily context is duly suspect.

## Institutional-level and Participation Factors

Institutional-level participation refers to localized ideologies of institutions that are adopted by the institution and perpetuated over time and place. For example, Western philosophy is privileged over Eastern (at least in the USA) and passed down through the scholars and students to the next generation of researchers. The issues presented in this paper represent many of the standard practices we have experienced in our clinical practice and research training.

Participation factors refer to the normative expectation placed on the criteria for participation in research. For example, in a majority of studies, consent to participate in research generally has to be verbal or provided by a verbal caregiver. This is a disadvantage to participation for people without families or natural alliances who navigate these barriers. Additionally, many disabled people are left out of research solely based on not using verbal communication as a primary mode. This is highly problematic in that, again, a normative modality is given precedence—even in fields of clinical research where verbal communication is frequently not the primary mode of communication.

Lastly, the focus on clinical outcomes trickles down from funding agencies—leaving us as a group with the questions of where and how to start to make institutional change. We hope to explore these topics and the connectedness between clinical research and HCI research as there is a substantial amount of HCI literature that stems from clinical methodologies. We aim to discuss the clinical pressures and use strategies to address these barriers as part of a larger approach to impact the HCI community—as this edge of the field of assistive technology has much it can gain from a disability studies perspective. In summary, the HCI research community should continue to engage in reflective practice and when necessary push past the established pedagogy that creates barriers to inclusivity. Failure to do so results in creation of knowledge that is only a truth to some.

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