Ethics and Human Subject Research

CSCI 497T/597T

What is Disability?

- Medical model
- Social model

What is Research?

- IRB oversight is confined to research
  - "Research" is work leading to generalizable knowledge
  - "Practice" (clinical medicine, product development, class projects) does not require IRB approval
  - But all work with human beings should follow the IRB ethical guidelines, even if it doesn't need to do IRB paperwork

Ethics of Human Subject Research

- Human subjects have been seriously abused in the past
  - MIT Fernald School study
  - Stanford prison experiment
  - Tuskegee Institute study

Fernald School & MIT Study (1940s-50s)

- MIT researchers studying calcium/iron absorption from breakfast cereal
  - enrolled children at Fernald School for children with mental disabilities
  - got parental permission, but omitted to mention the radioactive tracer isotopes

Stanford Prison Experiment (1971)

- Stanford psychologists studying people's responses to captivity
  - recruited Stanford undergrads to live in a mock prison, randomly assigned as either "guards" or "prisoners"
  - guards rapidly became abusive, and prisoners became traumatized

Tuskegee Institute Syphilis Study (1930s-72)

- US Government (Dept of Public Health) + Tuskegee Institute researchers
  - recruited 600 African American men, 399 with syphilis, without telling them, and studied the progress of the untreated disease
  - 28 participants died of syphilis, 100 died of related complications, 40 wives contracted syphilis, and 19 children were born with congenital syphilis

- Revelation in 1972 by a whistleblower, led to major changes in U.S. law and regulation on the protection of participants in clinical studies.

Basic Principles (Belmont Report)

- Respect for persons
- Beneficence
- Justice

Respect for Persons

- Voluntary participation
  - stop at any time without penalty
- Informed consent:
  - Participants should understand
    - Reason for conducting study
    - Procedures involved
    - Potential Risks
    - How they can get more information
  - Present this information clearly, accessibly, and without jargon

Respect for Persons

- Compensate when possible
- Provide comfortable surroundings
- Allow for flexibility in scheduling
- Try not to bias participants
  - "Don't you love the new tool that I built?"
- Aim for comparative studies
  - participants don't know which tool you developed.

Beneficence

- Do no harm
  - not just physical well-being, but also privacy
- Must weigh the risks vs. benefits
  - risks to participants should be commensurate with benefits of the work to the participants or to society as a whole
- Some scientific research can have substantial risk
  - Drug trials, medical devices
- Most HCI experiments are low risk
  - Fatigue? Eye or muscle strain?
- Social media, mobile, ubiquitous studies – novel privacy risks

Justice

- Fair selection of participants
  - opportunity to be in clinical trials of new treatments must be available to all (scientifically-appropriate) participants

Recruitment of Participants

- One of the biggest challenges is recruiting participants with disabilities
- How can you find participants with certain disabilities?
- Will they want to take part in your research?
- How far will you need to travel to visit them?
- Can lists of people with disabilities in an organization be provided (or are there privacy limits?)
- Are there existing pools of participants with disabilities?

Recruiting through Community Partners

- To help recruit participants, it is a good idea to form a collaboration with a disability group based in the community

- The group may be interested in your research, and may be able to help you recruit participants

- Note, that it must be a partnership, a two-way street; The community group must also benefit

- You can't just do "drive-by research"

- Make sure to keep the group involved, informed, and consult with them regularly; ask the group what research most needs to be done

Methodological Approaches

- Smaller sample sizes are acceptable in research on people with disabilities
  - 5-10 users is sufficient if they are the *right* users
- Distributed research, crowdsourcing, where the users do the research in their home or office, without researchers present, and send the data
- In-depth case studies, with fewer users, taking part in a more intensive way, over a longer period of time

Communication

- Understand the preferred method of contact
  - Deaf people will not prefer phone calls unless you are using sign language over video
  - Blind people have high spam filtering and often won't read e-mails that are sent their e-mail address as a BCC (blind carbon copy)
  - For users with Alzheimer or Dementia, it may be necessary to contact caregivers

General Rules

- Be respectful of others
- - People have different experiences with disability and assistive technology
- - Don't be afraid to ask questions or voice your thoughts!

True or False

1. When meeting someone who is blind, always identify yourself verbally (e.g., "Hey, it's me, Michelle.")
2. You should offer assistance to someone with a disability without being asked.
3. If you are having difficulty understanding someone, it's OK to nod and keep the conversation flowing.
4. You should always use "people-first" language, e.g. "person with a disability" or "person with Down syndrome", instead of "disabled person", "paralyzed person", or "blind person."
5. You should not use terms like "see you later" or "did you hear about this?" to someone who has a vision or hearing disability.

The 10 commandments of communicating with people with disabilities, 1994.

- Speak Directly to the person
- Offer to shake hands
- Identify yourself when speaking to a person who is blind
- Wait for a response and instructions when offering assistance
- Treat adults as adults
- Do not hang or lean on a person's wheelchair
- Listen attentively
- Speak to people at eye level
- Tap a person who is deaf on her/his shoulder
- Relax!

10 Commandments of Communicating with Persons with Disabilities is a short 20 minute video tape training. It's training that uses humorous vignettes to deliver its disability awareness message.

https://www.youtube.com/watch?v=zpPhQl4seqk

People-First Language

SAY:	INSTEAD OF:
People with disabilities.	The handicapped or disabled.
He has a cognitive disability/diagnosis.	He's mentally retarded.
She has autism (or a diagnosis of...).	She's autistic.
He has Down syndrome (or a diagnosis of...).	He's Down's; a mongoloid.
She has a learning disability (diagnosis).	She's learning disabled.
He has a physical disability (diagnosis).	He's a quadriplegic/is crippled.
She's of short stature/she's a little person.	She's a dwarf/midget.
He has a mental health condition/diagnosis.	He's emotionally disturbed/mentally ill.
She uses a wheelchair/mobility chair.	She's confined to/is wheelchair bound.
He receives special ed services.	He's in special ed.
She has a developmental delay.	She's developmentally delayed.
Children without disabilities.	Normal or healthy kids.
Communicates with her eyes/device/etc.	Is non-verbal.

People with Blindness

- Blind users cannot use printed material (and many of them cannot read Braille, either)
- Physical settings (if they come to you)
  - Are they bringing a guide dog?
  - Does your building have Braille labels on doors and elevators?
- Usage patterns may also play a role (e.g., a user who listens to a screen reader at a very high rate of speed)

Participants who are Deaf or Hard of Hearing

- Determine in advance whether participants are fluent in sign language and whether interpreters (and how many) will be necessary

- Other forms of accommodation may be necessary (e.g., oral interpretation, induction/hearing loops, etc.)

- Remember that people who identify as hard of hearing may not be sign language users

Proxy Users?

- Is it OK to use "proxy users" (without disabilities) to represent actual users with disabilities? In general, NO!
  - Do NOT blindfold users, to simulate blindness, or tie hands behind their back, to simulate motor impairment
- Proxy users are only acceptable when the users with disabilities are either:
  - Unable to communicate, Unable to process information
- Pairs of users and caregivers can be OK

Working with Children

- Parents *consent*

- Children *assent* - agree to participate

- Allow parents to observe
  - But not interfere..
  - At least for younger children

- Appropriate rewards and task structure
  - Meet children's cognitive capacities

Scheduling and Location

- Many users with disabilities do not drive a car
  - They take public transportation, taxis, or use scheduled services
- It often is not possible to make last minute schedule changes
- Be aware that employment is a point of pride for someone with a disability, and they are not likely to miss work for your research
  - Offer to do the research on nights or weekends

Scheduling and Location

- You should offer to do the research at the user's workplace or home—it should be an option
  - It removes issues related to accessibility barriers in your research lab, as well as any transportation issues for users
- Workplaces or homes give a glimpse of the user in their own comfortable environment, both the physical environment and the technical environment

Documentation

- Make sure that the documentation is accessible for all participants are taking part in your research
  - Informed consent forms, task lists, instructions, may be problematic for people with print-related impairments (blindness, low vision, dyslexia, or motor impairment that keeps them from handling printed materials)
- Send any preliminary documents (e.g., informed consent forms) via email beforehand in electronic format
- Offer to read any documents out loud, or maybe provide audio recordings

A signature guide for participants who are blind (make sure that they understand what they are signing)

Pilot Studies

- Pilot studies are necessary

- Your expectations and perceptions are likely to be very different from reality

- Since you will have access to a limited number of users in the main stages of the research, you want to make sure that you get your research methods and logistics perfected before you start

- One or two pilot users is sufficient

Closing thoughts

- Participants are crucial – treat them with respect, beneficence, justice
- Allow plenty of time
- Food and drink
- Breaks as needed
- Make participation fun!

Activity

- Research with people is subject to scrutiny
  - All federally-funded institutions have an *institutional review board* (IRB) that approves human subjects research
  - IRB at WWU https://www.wwu.edu/compliance/irb-about.shtml
- Complete your WWU IRB training
  - https://www.wwu.edu/compliance/training.shtml