

# CMPE 80A: Universal Access: Disability, Technology, and Society



Working with People with Disabilities



## Working with participants

- ▶ Research oversight<sup>1</sup> is needed
  - Too many clinical trial blunders
  - The future impact of such issues as cloning, gene therapy, genetic engineering, etc. is unknown.
- ▶ History: Nuremberg Code
  - Informed consent is essential.
  - Research should be based on prior animal work.
  - The risks should be justified by the anticipated benefits.
  - Only qualified scientists must conduct research.
  - Physical and mental suffering must be avoided.
  - Research in which death or disabling injury is expected should not be conducted.

<sup>1</sup>a system for addressing questions of potential risk through guidelines, regulations or other structures



## Working with participants

- ▶ History: Declaration of Helsinki (1964)
  - Nuremberg Code + medical research with therapeutic intent (World Medical Association)
- ▶ History: National Research Act of 1974
  - Established "National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research"
  - Required establishment of IRBs at institutions receiving the Department of Health and Human Services funding for human subjects research
- ▶ History: Belmont Report (1979) – Govt of USA
  - Established the basis for the ethical principles upon which federal regulations for protection of human subjects are based



## The Institutional Review Board

- ▶ Mandated for all institutions conducting human research.
  - Any study intended to result in publication or public presentation, including classroom projects.
  - Any activity resulting in publication or public presentation, even if it involves only review of existing data that was collected with no intent to publish.
  - Any use of an investigational drug or device.
- ▶ Exempt → non research
  - Employee evaluation, program evaluation, quality assurance, or other situations where such evaluation is not designed to lead to generalizable knowledge



## The Institutional Review Board

- ▶ Roles and responsibility.
  - Review research plan to be sure it meets criteria in Federal regulations
  - Confirm there are no unreasonable risks
  - Conduct continuing review
  - Assess suspected or alleged protocol violations.
- ▶ Authority
  - Approve, disapprove, or terminate all research.
  - Require modifications to protocols.
  - Require that information the IRB deems necessary is provided to participants.
  - Require documentation of informed consent, or allow waiver of consent.



## Types of IRB Review

- ▶ Full board review
  - For research involving risk of physical or psychological harm greater than that encountered in daily life, particularly research involving deception, stress, or manipulation
  - Research with vulnerable population
- ▶ Expedited review
  - Collection of data through noninvasive procedures, such as weight, blood pressure, flexibility testing, etc)
  - Materials (data, documents, records, or specimens) that are collected solely for non-research purposes.
- ▶ Administrative review
  - Research conducted in accepted educational settings
  - Research involving only observation of public behavior
  - Research involving only surveys or interviews



## What to submit to IRB

- ▶ Protocol statement (What is to be done.)
- ▶ Consent forms OR
- ▶ Assent forms (for children 7-17 years old)
- ▶ All personnel involved and their qualifications
- ▶ Location for study
- ▶ Special populations, if any
- ▶ Data collection method – a copy of the questions might be needed
- ▶ Recruitment ads
- ▶ Source of funding
- ▶ Payment to subjects
- ▶ Costs to subjects
- ▶ Benefits to subjects
- ▶ Risks and discomforts
- ▶ Confidentiality – how confidentiality will be maintained for records, videotapes, audiotapes, and how records will be destroyed at end of study.



## Recruitment

- ▶ Add recruiting time and expenses
- ▶ Make key contacts → difficult to open communication otherwise
- ▶ Check ethical issues
- ▶ Conduct preliminary tests early → some people might need way more extra time that you had anticipated
- ▶ Plan higher expenses (transport cost, a carer, etc)
- ▶ Consider their needs (wheelchair access, blind-friendly environment, etc)
- ▶ Plan time for participants to become comfortable and familiar with the environment
- ▶ Be ready to do some work at participants' home
- ▶ Make sure all materials are available in necessary formats.



## Preparing the Study

- ▶ Include consent forms with the materials sent ahead of time (ask which format)
- ▶ Use a checklist to ensure that you have anticipated any potential barriers → evaluate the accessibility of potential locations
- ▶ Schedule a walkthrough by a person with similar accessibility needs
- ▶ Be familiar with the Assistive Technology the participants need to use → Schedule time to set up and test AT
- ▶ Make sure everybody involved in the session are properly trained on issues associated with dealing with persons with special needs → training can take a while



## At the Session

- ▶ Don't make assumptions
- ▶ Ask before you help – general rule, be courteous, but NOT condescending
- ▶ Speak normally unless requested otherwise
- ▶ Avoid potentially offensive terms or euphemisms → 'mentally different', 'physically inconvenienced', or 'physically challenged'
- ▶ Make everybody that will be there aware that there will be session with people with disabilities
- ▶ Practice "not staring" → or apologize in advance
- ▶ Don't pause (or "errrr.....") to avoid certain words
- ▶ Be aware of personal space
- ▶ Don't interact with a service animal
- ▶ Don't act like a carer
- ▶ Consider how you would introduce yourself and explain the protocol to the participants



## Terms to use

- ▶ Person-first terms i.e. 'a person with wheelchair' NOT 'a wheelchair-bound person'
- ▶ Person (with a) or (has sustained) or (with and acquired) brain injury
- ▶ Person [living] with AIDS/HIV
- ▶ Down syndrome NOT 'mongoloids'
- ▶ Cleft lip NOT 'hare lip'
- ▶ Non-disabled NOT 'normal', 'able-bodied' or 'healthy'
- ▶ Stroke survivor NOT 'stroke victim'
- ▶ People with disabilities NOT 'the disabled' or 'handicapped people' → people with disabilities are not generic
- ▶ Mature or older person NOT 'the elderly'
- ▶ Person with epilepsy or seizure disorder NOT 'epileptic'
- ▶ Purge terms like: 'crippled', 'lame', 'deformed', 'decrepit' or 'poor thing'



## Specific Consideration for Working with Persons who are Blind or VI

- ▶ Introduce yourself as you approach the participant
- ▶ Introduce others who are in the room.
- ▶ Describe the setting to the participant, including the position of the video camera.
- ▶ Tell the participant when you or others enter or leave the room.
- ▶ Give directions about where to be seated. Ask the participant if he or she would like to be guided to the chair.
- ▶ Offer your elbow to lead the participant. Don't grab the participant's arm, hand, or cane.
- ▶ Tell the participant where there is room for the service animal.



## Specific Consideration for Working with Persons with Communication Impairment

- ▶ Admit if you don't understand, ask them to repeat
- ▶ Don't speak slowly unless requested
- ▶ Some prefer to write their communications down on paper – be patient
- ▶ Some will require communication aid (AAC) – understand how this system works
- ▶ Be flexible – you may need to change to yes/no or binary option in communicating
- ▶ Be careful before “filling-in the gaps”
- ▶ Wait for the response longer than you normally would, they might take more time formulating answers



## Specific Consideration for Working with People who are deaf or HI

- ▶ Get the participant's attention before talking. Touch the person gently on the shoulder or arm.
- ▶ Take turns talking. A person who speechreads might miss information if two or more people talk at the same time.
- ▶ Face the participant while speaking, and speak at eye level.
- ▶ Clarify to the interpreter the importance of translating questions and answers exactly.
- ▶ Don't speak too loud. Some hearing aid and cochlear implant users are especially sensitive to loudness.
- ▶ Offer to write down what you are saying



## Specific Consideration for Working with People with Physical Impairments

- ▶ Do not move mobility aids. Some people are uncomfortable if the aids are out of reach.
- ▶ Remember seating for a personal attendant if needed.
- ▶ Have a clipboard available to hold the consent form and instruction sheet.
- ▶ Remember space for a wheelchair, a cane or other mobility aids.
- ▶ Offer to write down their answers (but be careful how you ask).
- ▶ Some may have difficulty getting in and out of soft and low seating. Provide upright, rigid seating (or better, adjustable)



## Specific Consideration for Children

- ▶ Arrange furniture so that children are not directly facing the video camera and one-way mirror
- ▶ Timetable a session of max 1 hr (30 min for pre-schoolers) and integrate play in breaks
- ▶ Check whether you need parents to sign consent form (most likely yes)
- ▶ Children up to 7 or 8-years-old will need a tester in the room with them for reassurance.
- ▶ If a parent will be present in the room, explain to the parent to minimise interaction with her children
- ▶ use phrases such as “Now I need you to...” or “Let's do this...” or “It's time to...”



## Specific Consideration for Older Adults

- ▶ They often arrive early (as they are retired), make sure somebody is around
- ▶ They often come with their spouses, anticipate space for spouses.
- ▶ They often do best in the morning, avoid scheduling late evening appts.
- ▶ They don't like driving at rush hour (if they drive at all), don't schedule too close to rush hour.
- ▶ Remind them very close to the appt date what to bring (e.g. reading glasses), place and time.
- ▶ They often assume food is provided, inform them if that is not the case (so they can bring some, especially for long sessions).
- ▶ They often deviate with long stories about their offspring. Be tactful to keep them on track (they might leave if feeling offended).
- ▶ Some older women are very sensitive of smells, or if somebody shows the sign of illness.

