Doing research with people with disabilities

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This deck should help us:

- → be aware of the <u>spectrum of</u> <u>disability</u>
- → learn methods to <u>support a</u> <u>disabled person during research</u>
- → understand what to do in potential situations
- → find <u>further resources</u>

Disability is a spectrum

Disabled people can include:

- → people with cognitive impairments
- → people with functional disabilities
- → people with multiple disabilities

Around 25% of all Veterans have a service-connected disability.

It's important to remember that:

- → every disability is different
- → people with the same disability might be impacted or present differently to one another
- → disabled people often receive poor care or treatment which affects their trust and expectations

Traumatic brain injury

A traumatic brain injury occurs when a sudden trauma causes damage to the brain. It can impact cognitive or thinking skills, communication or speech, physical or sensory functions, emotions and behaviours.

- → struggle to remember things
- → get frustrated easily or react strongly and often
- → be easily confused or disoriented

Aphasia

Aphasia is a neurological disorder caused by damage to the portions of the brain that are responsible for production or processing. It can result from a stroke, brain tumor, head injury or dementia.

- → have difficulty expressing themselves
- → have difficulty finding the right words for objects, people, places or events

Posttraumatic Stress Disorder

Posttraumatic Stress Disorder (PTSD) is a mental health condition that is triggered by a terrifying event. Symptoms can include intrusive memories, avoidance, negative changes in thinking or mood, and changes in physical or emotional reactions.

- → feel irritable or react strongly and often
- → be untrusting or hesitant of others
- → be less able to express their emotions

Deaf or hearing loss

People can be deaf or have hearing loss to varying degrees. They may use hearing aids, sign language interpreters, lip reading or other assistive technology.

- → rely on lip reading
- → need rephrasing or repeating
- → use an interpreter or other assistive technology

Mobility disability

A mobility disability can affect a range of different movements, such as walking or writing. People with mobility disabilities use different devices, like walkers, wheelchairs or other assistive technology to support them.

- → use different assistive technologies to use computers or write
- → need a table that is height-adjustable or at the right height
- → need more time during breaks

When we support people well during research, we're more likely to not cause harm, identify people's needs and build better services

General tips

- → Let people know what to expect
- → Ask one question at a time
- → Reframe anything that is unclear or give options
- → Avoid jargon or explain a term if you need to use it
- → Notice changes in a person's behaviour
- → Ask if someone needs help instead of assuming
- → Avoid completing the interviewee's sentences
- → Offer to take a break
- → Work as a team

- → Let participants sit facing the entrance of the space
- → Include a woman or non-binary researcher in each interview
- → Avoid or ask for permission to shake hands
- → If a support animal is allowed in the space, have water available and don't bother or pet them

Tips for people with hearing loss

- → Provide questions in advance, if possible
- → Ensure the room is well lit
- → Sit where the light is facing you, not behind you
- → Help language professionals by including extra chairs and preparing advice for them so they understand the purpose of the study
- → Speak clearly and at a normal speed
- → Have a pen and paper available if needed
- → Let someone view any stimuli before asking questions

Tips for people with mobility disabilities

- → Confirm the space is accessible
- → Ensure table can fit a wheelchair or use a height-adjustable table
- → Provide space to place mobility aids (such as a cane) nearby
- → Have a chair available for wheelchair users, if they choose it
- → Sit at the same level as the person you're speaking to, if possible
- → Do not lean on or touch someone's mobility aids unless they ask

Scenario: Confusion

You ask a question and the participant looks confused or tells you they don't understand.

- → give more context
- → use different words
- → use a picture or draw
- → simplify
- → offer options or make a question more closed

Scenario: Difficulty remembering

You notice that a participant regularly goes off topic or struggles to remember what you asked them.

- → use their name
- → remind them of the task
- → break down the task or question even further
- → suggest taking a break

Scenario: Distress or harm

Something you mentioned causes a participant to react strongly or become distressed.

- → suggest changing topics
- → suggest taking a break
- → end the session
- → ask whether they have a person or place to receive support now
- → provide after-care resources such as <u>The Veterans Crisis Line</u>

Scenario: Supporter

A participant has a caregiver who asks to join the interview with them.

- → ensure the participant is fully informed and consents themselves
- → address the participant directly
- → let the caregiver and participant interact, but take note if they are leading

"Disability justice means we are not left behind; we are beloved, kindred, needed." Leah Lakshmi Piepzna-Samarasinha

Further resources

- → Supporting Justice: Communication with people with a disability
- → Bright Harbour: Participant wellbeing pack
- → Interviewing people with disabilities
- → Paper Studio: User research patterns
- → Leah Lakshmi Piepzna-Samarasinha: Care Work
- → Sasha Costanza-Chock: "Nothing About Us, Without Us"
- → Rachael Dietkus: Trauma-Informed Design Research
- → Kate Stulberg: Researching with vulnerable people
- → Tyler Gindraux: Doing research with people with hearing loss
- → Sarah Fathallah: Trauma-responsive participatory research
- → VA Application Team's trauma practice working document
- → VA Research Safety and Emergency Exit Strategies
- → Join #inclusive-research on Digital Service @ VA Slack