INCLUSIVE RESEARCH

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With contributions from Mary Elizabeth Sullivan and Glenda Sims

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UNDERSTANDING DISABILITIES

PEOPLE WITH DISABILITIES AS A MARKET

LEGAL IMPLICATIONS OF DISABLED EXCLUSION

WHY SHOULD WE MAKE RESEARCH INCLUSIVE

MAKING RESEARCH INCLUSIVE

- Mind Your Manners
- Design Inclusively
- Be Accommodating
- Be Willing to Modify

My Experience

Photo by Nathan Anderson on Unsplash

Cherry Rae, My Neighbour

Cherry Rae, Gamer

Cherry Rae, Person with Disabilities

Cherry Rae, Advocate and Consultant

WHAT IS YOUR DISABILITY EXPERIENCE?

Photo by Yomex Owo on Unsplash

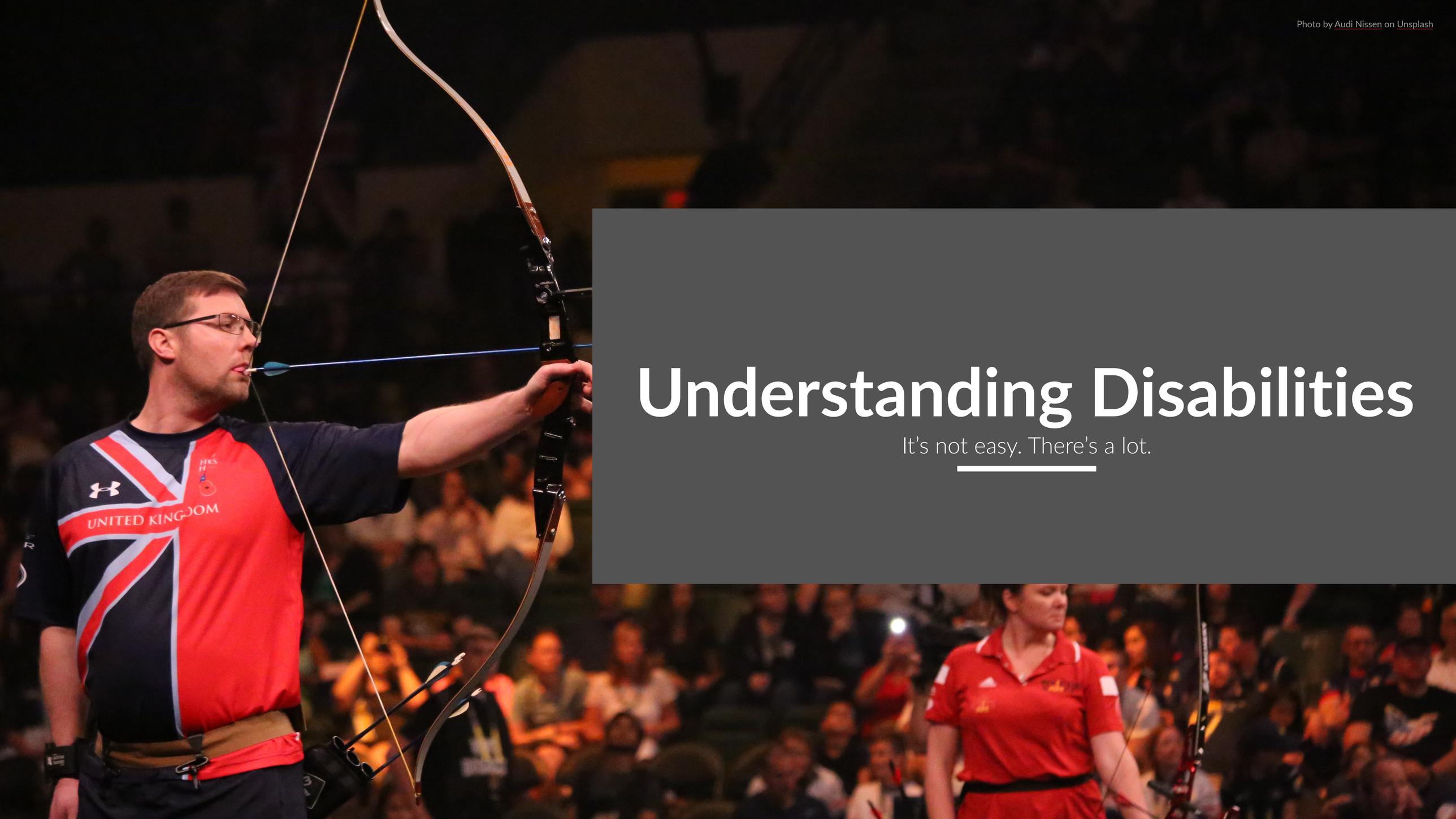


Photo by Audi Nissen on Unsplash

Understanding Disabilities

It’s not easy. There’s a lot.

Major Types of Disabilities

Complexity is easier as an abstraction

PHYSICAL

Affect's a person's mobility and/or dexterity

INTELLECTUAL/LEARNING

Learn or process information differently

PHYCHIATRIC

Stress related, depression, bipolar disorder, anxiety, and schizophrenia

VISUAL IMPAIRMENTS

Only 5% are completely blind. Lots of variation.

HEARING IMPAIRMENTS

Not necessarily deaf to be hearing impaired.

NEUROLOGICAL

Associated to damage to the nervous system.

Great Variation Within Categories

But it's still complex

Visual Impairments

Disability as a Continuum

One Arm

Something that works for someone with one arm will also work for people with a temporary or situational disability.

Permanent

Temporary

Situational

People With Disabilities

The size of the market

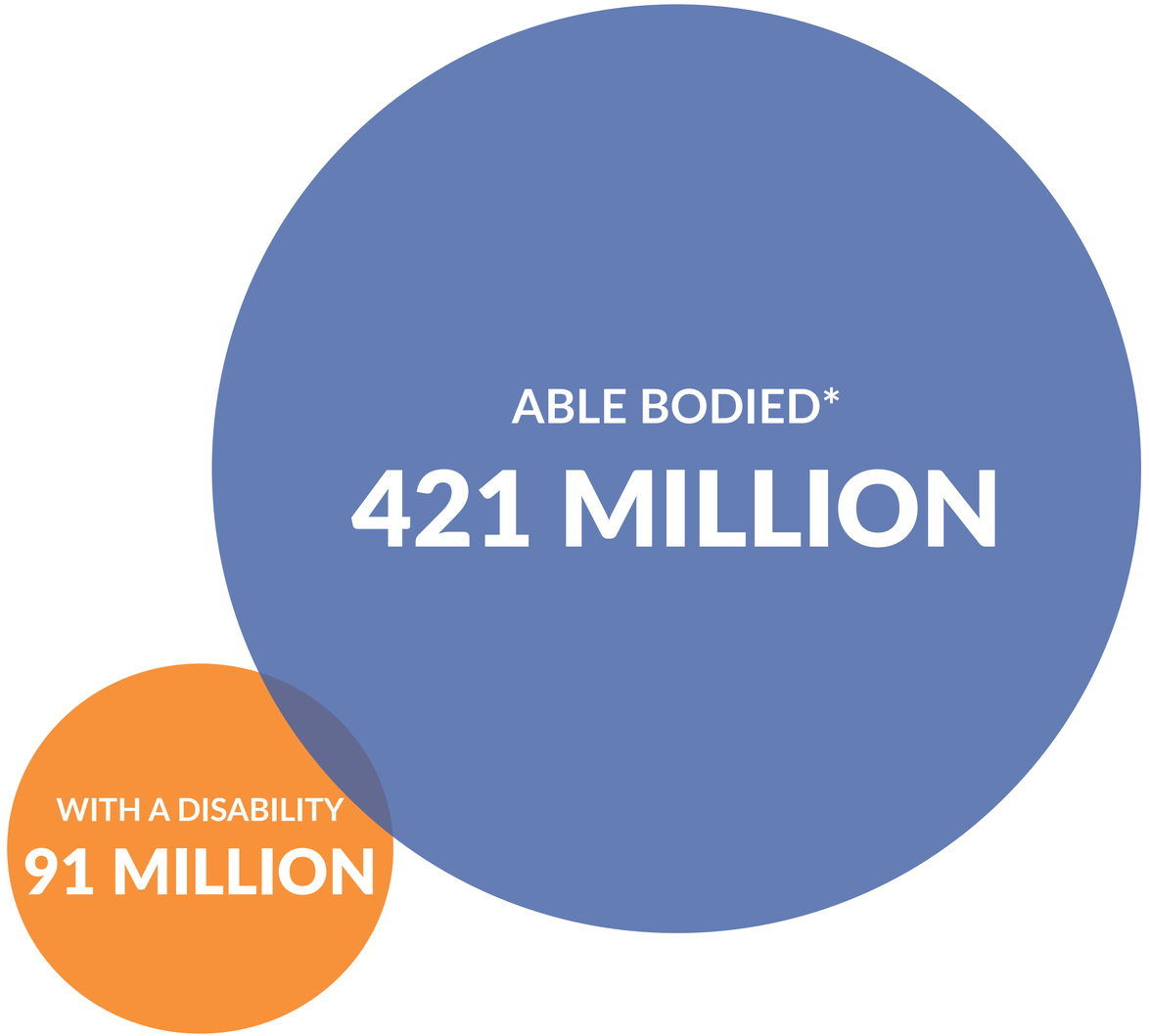
Photo by Audi Nissen on Unsplash

Disabilities by the Numbers

Europe

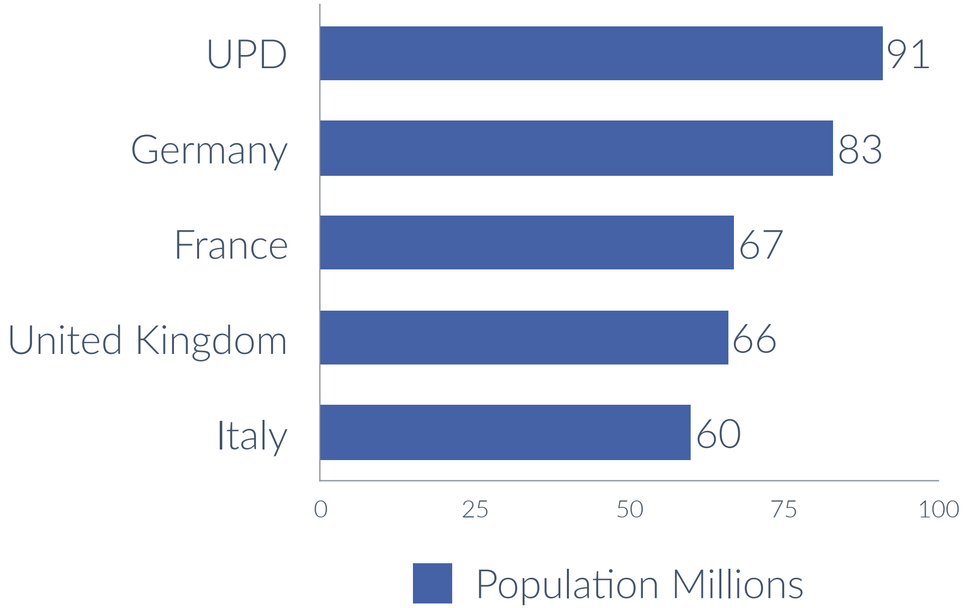
- 18% identifies as having a disability

* Many people technically have a disability but do not identify as such.



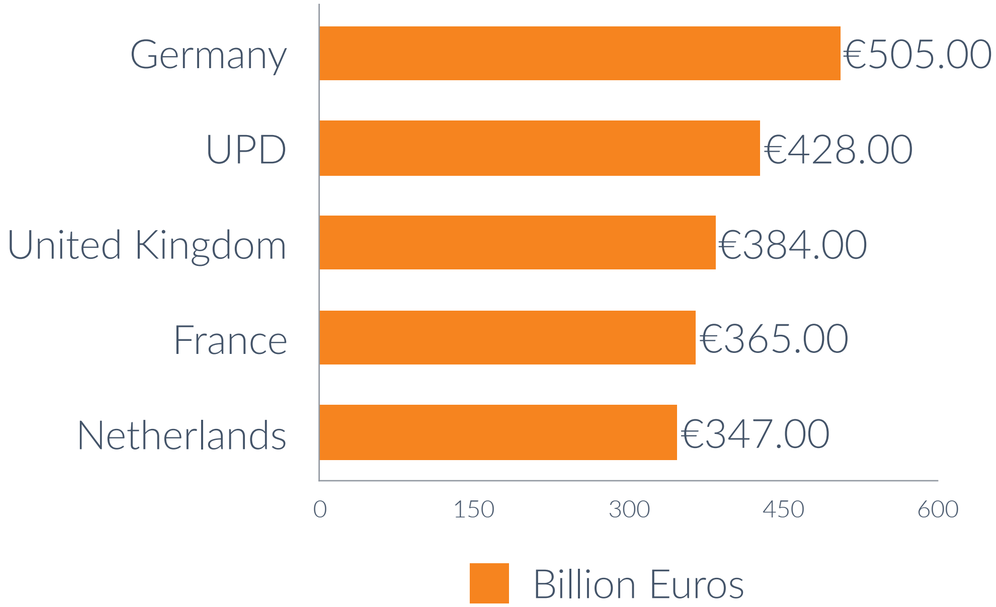
United Peoples With Disabilities

Bigger than Brexit, but not Brexit



Population

Largest country in the EU

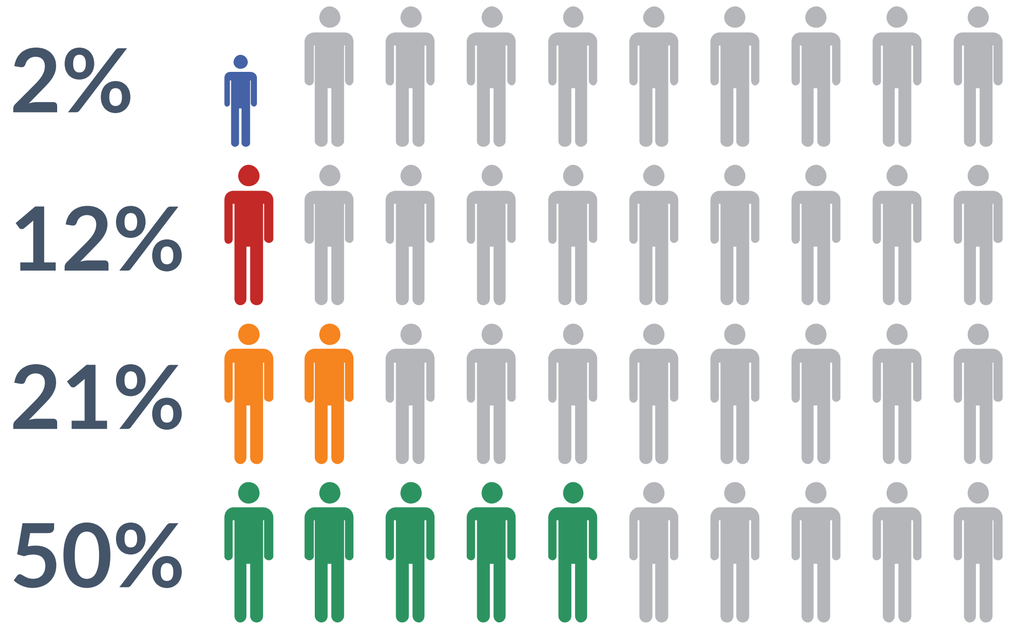


Disposable Income

Second largest disposable income

Disability Rates Increase with Age

We are getting older and less abled every day



Children younger than 3-years

School aged children

15-years and older

65 and older

Legal Implications

Exclusivity Is a Liability

Photo by Robert Ruggiero on Unsplash

European Union of the Deaf

New Europe

Autism Europe

New Europe

European Accessibility Act (EAA)

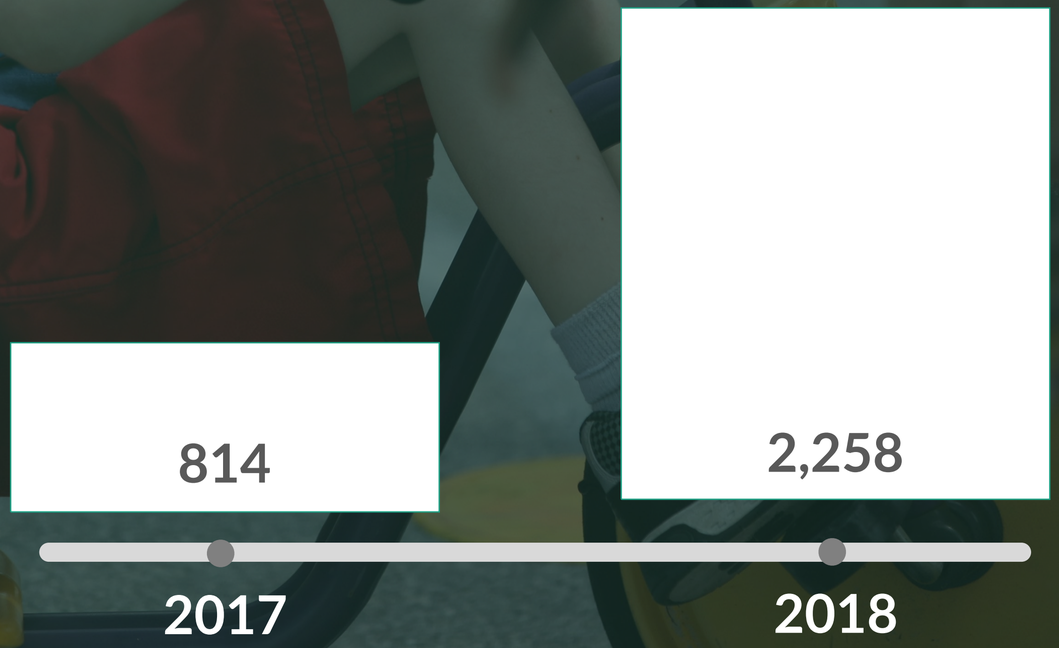
The EAA is intended to encourage companies to integrate accessibility into their development process instead of as an afterthought.

- Ticketing and check-in machines
- Computers and operating systems
- Smartphones
- Digital TV services
- Telephones
- Banking
- AV media
- E-Books
- E-Commerce
- Transportation

Lawsuits Are on the Rise

Inaction is a Liability

277% Increase in civil lawsuits under the ADA



Seyfarth Shaw
SHRM
Marine Base Camp Lejeune

Exclusion is Everywhere

Not just the web

Restaurants

- High tables
- Bench seating
- Crowded table layout

Amusement Parks

- Rides not accommodating wheelchairs

Bathrooms

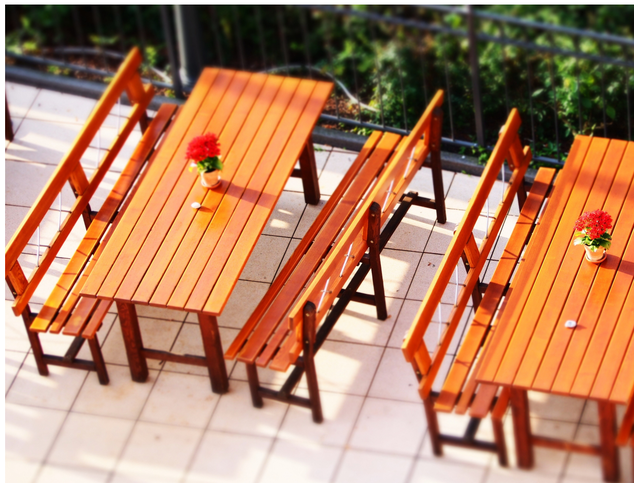
- Too small for mobility aids
- Mirrors not tilted down

Video Games

- Visuals that cause vertigo
- Controllers requiring high dexterity

We don’t think about it because we don’t have to. *That’s privilege*.

Wikipedia



Why Make Research Inclusive

It’s more than a kindness

Photo by Carlos Navas on Unsplash

Healthcare Research

They ARE the target market

People with disabilities are often excluded from healthcare research even though they experience poorer health, greater incidence of chronic conditions, and higher health care expenditures than people without disabilities.

Health care for adults with disabilities amounts to roughly €407 billion per year, and represented approximately one quarter of 2017 health care expenditures in Europe.

EuroStat

National Institutes of Health

User Experience Research

They’re more than an edge case

Companies with a web presence who do not build and test for accessibility are vulnerable to lawsuits. Ignorance and edge cases are no longer excuses. Solving for “edge case issues” makes systems easier to use for everyone.

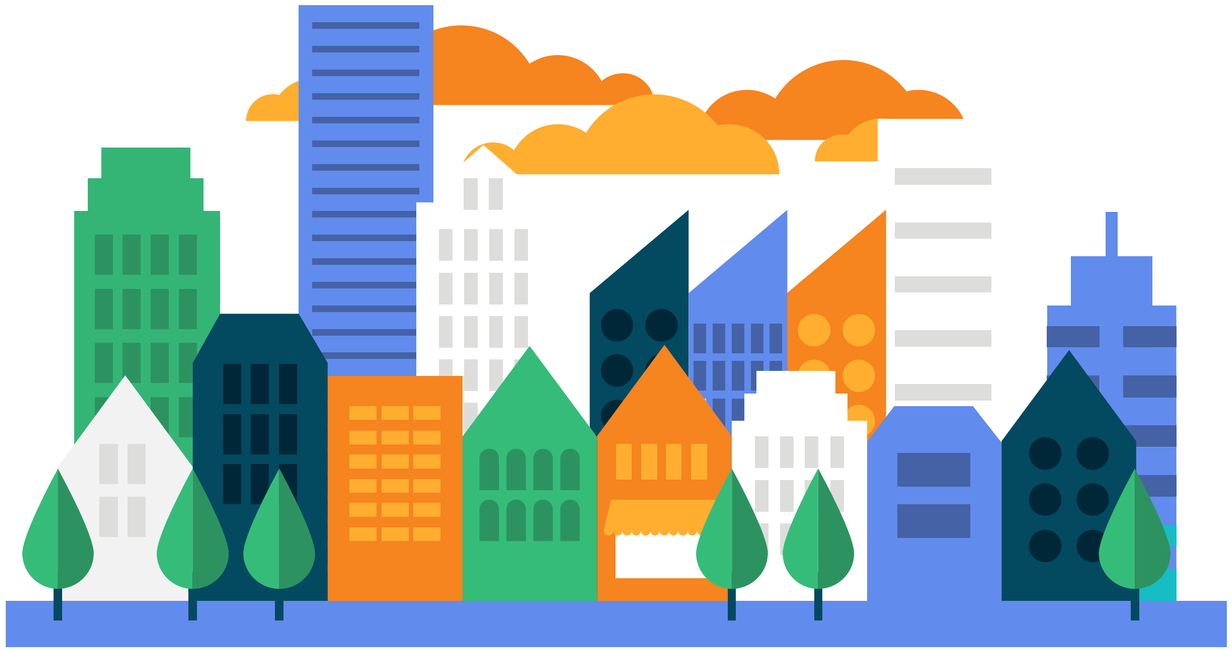
While sites may be technically accessible, this may not ensure their usability for people with disabilities. Research and testing matter.

Political and Policy Research

They ARE the constituency

Governments, political leaders, and policy makers have a responsibility to serve the entire populace.

A good way to ensure a policy, an initiative, a service, or a facility is inclusive is through ensuring racial, economic, and ability diversity during every research activity.



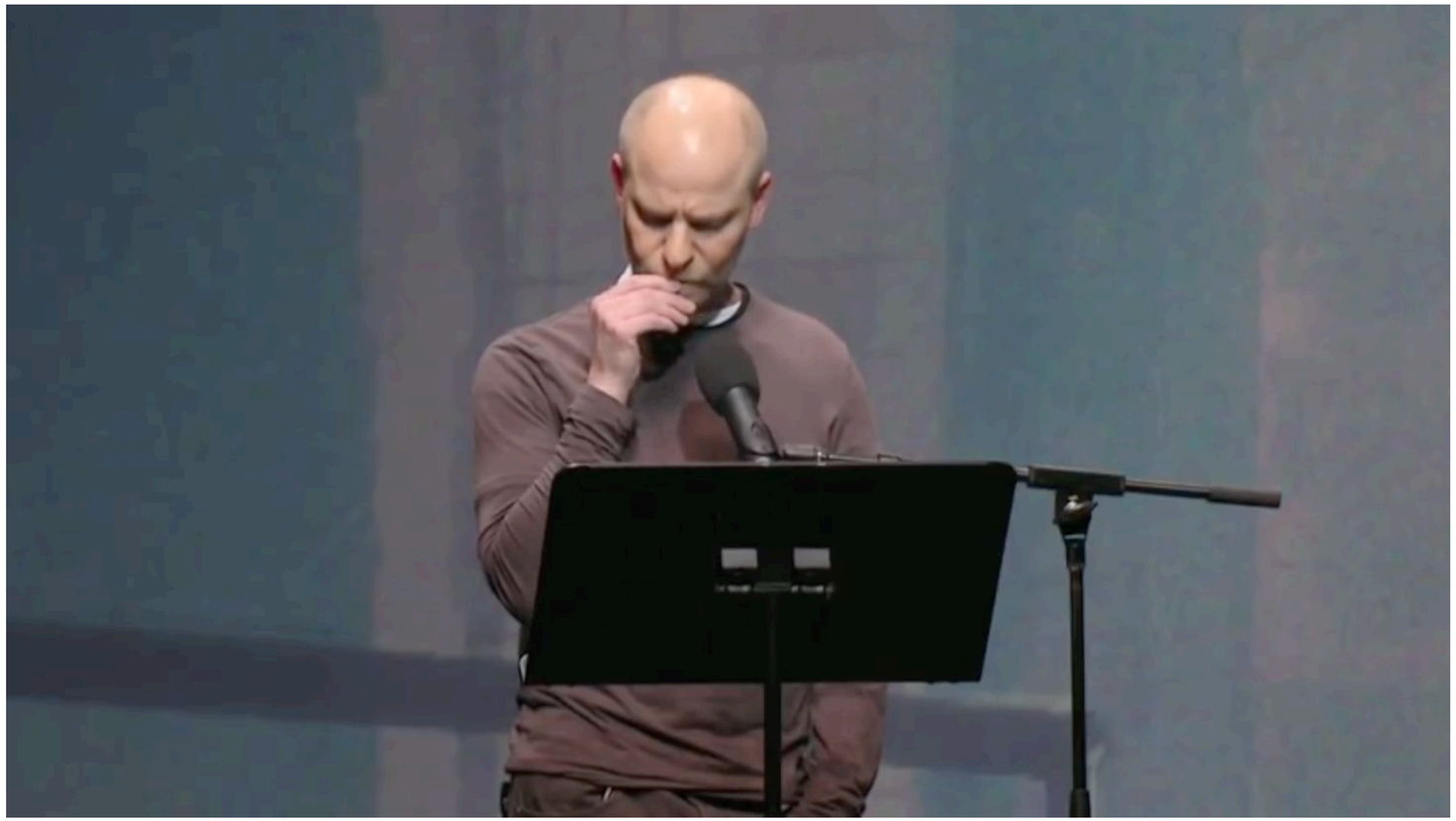
Innovation Research

They’re creative AF

People with disabilities exercise and utilize high levels of creativity daily to do the relatively mundane things we take for granted, a characteristic most clients should be grateful to hear from.

Innovation Research

When the mundane is a challenge



Humorist, David Rakoff, lost the use of his arm as a side effect of radiation treatments for cancer.

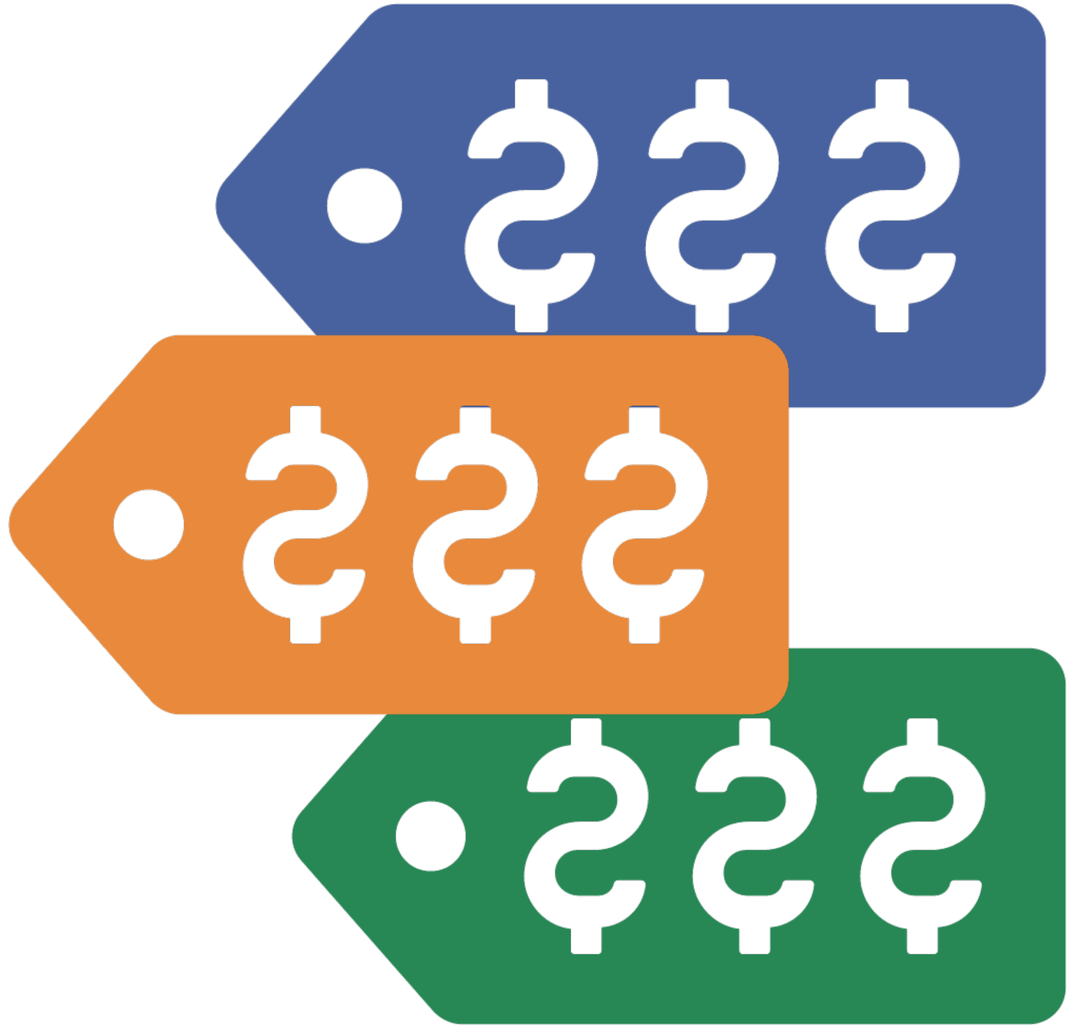
Listen to him explain the hacks he uses to do some of the common chores we take for granted.

This American Life

Higher Production Costs

Settlements add up to more than just the fines

Trying to retrofit accessible features after the fact can increase production costs by a factor of 10,000



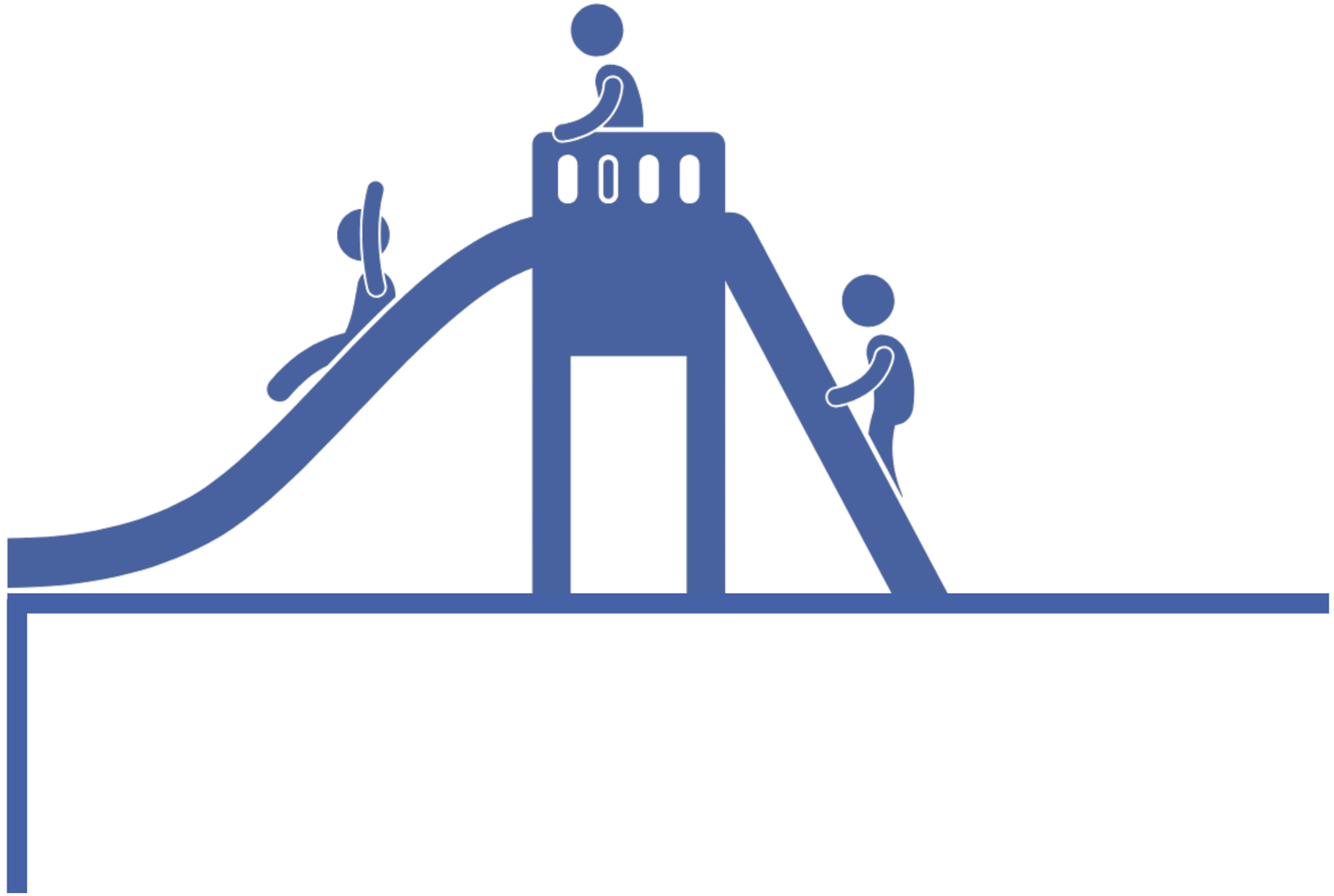
Making Research Inclusive

How?

Photo by Charles 🇵🇭 on Unsplash

Just Enough Know-How

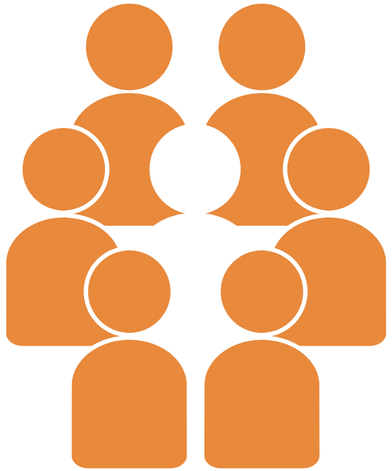
Enough to make you dangerous



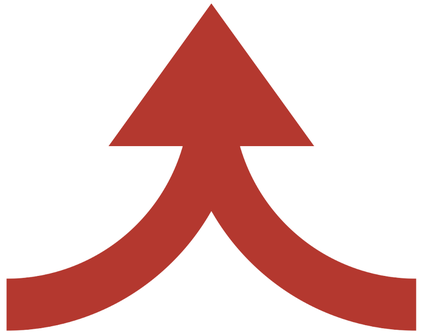
How Do We Make Research Inclusive?

Four elements of inclusive research

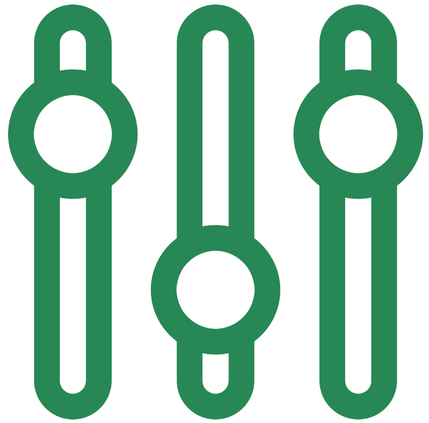
MIND YOUR MANNERS



DESIGN INCLUSIVELY



BE ACCOMMODATING



BE WILLING TO MODIFY

MIND YOUR MANNERS

IT PAYS TO BE POLITE

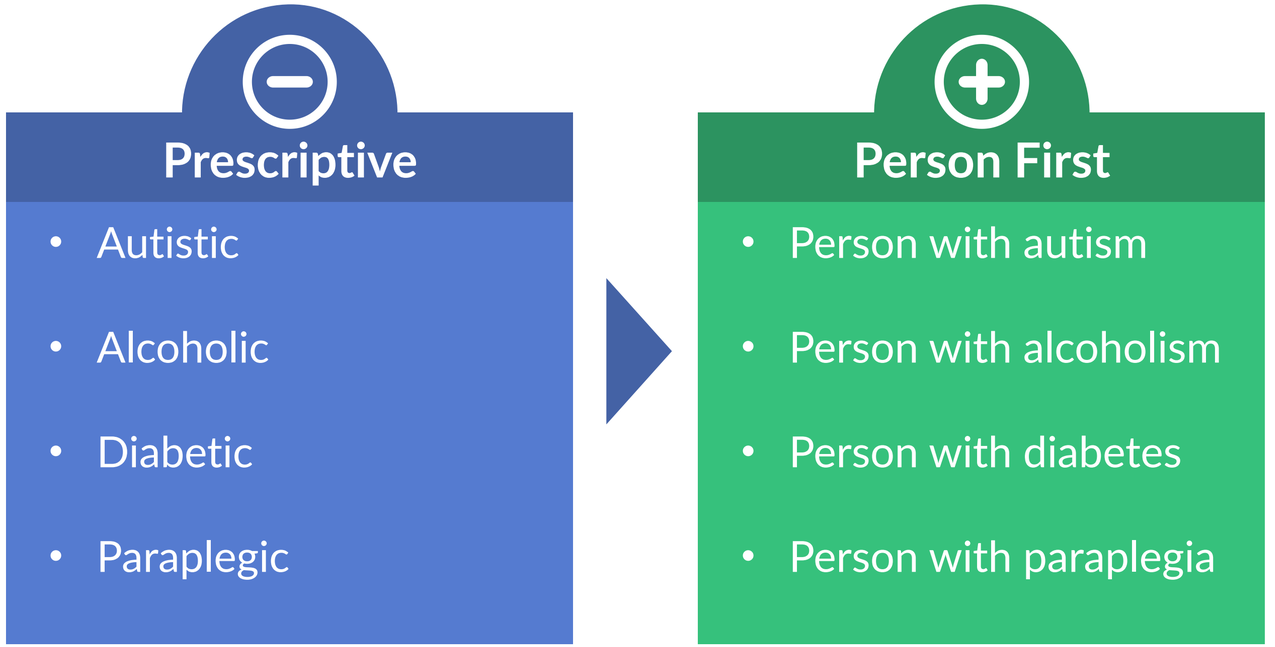
Person First Language

Person WITH a Disability

Puts the person before the diagnosis.

Describes what a person ‘has’ instead of what a person ‘is.’

Disassociates the person from the disorder, disease, or affliction.



Statistics Canada

Wikipedia

Just Ask

Remember, not everyone who has a disability identifies that way.

Sometimes your best best is to just ask how they would like to be referred to or treated.

Interaction Etiquette

Provide the right help, at the right time

Speak directly to the person with the disability, not their interpreter or their companion.

Don’t assume they need help. Always ask first.

Don’t touch them, their assistive devices, or their service animals without permission.

Be attentive and patient when you’re talking with someone who has trouble speaking.

If you’re unsure what to do or how to make someone comfortable, ask.

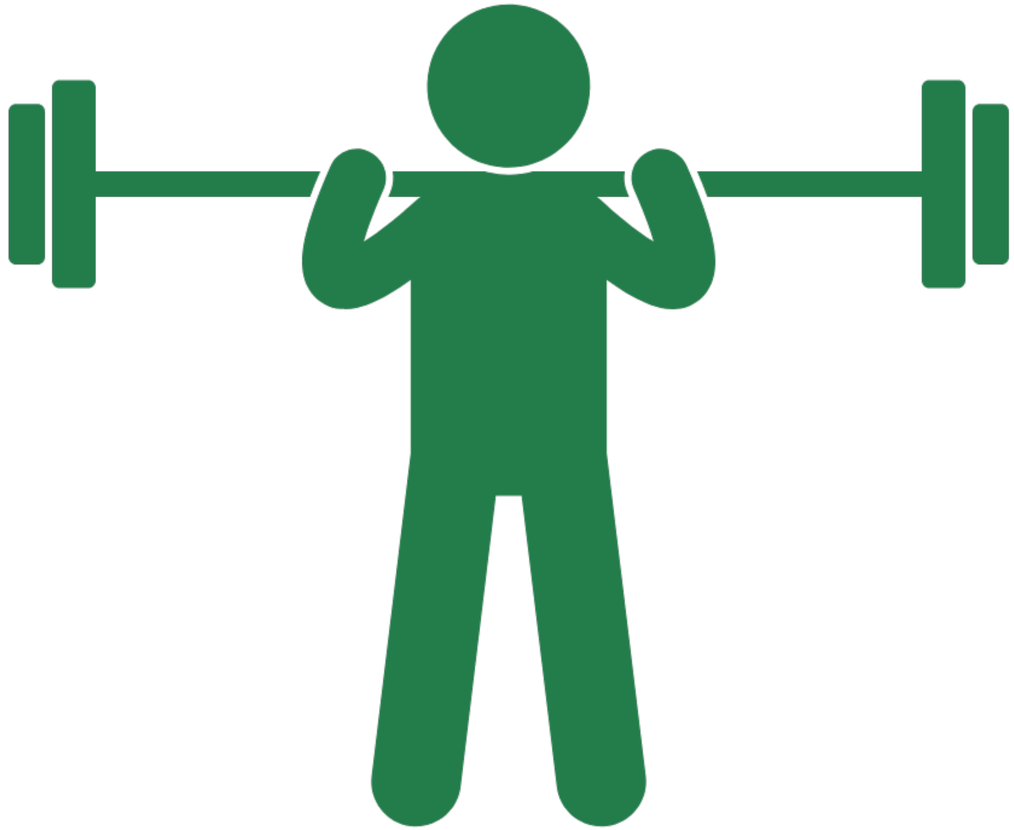
Build Your Empathy

Volunteer, attend Meetups, hire and foster an inclusive work culture for people with disabilities.

Use communication tools made by and for people with disabilities or healthcare providers.

Ask dignified questions and trust people.

Don’t get caught in simulators.



DESIGN INCLUSIVELY

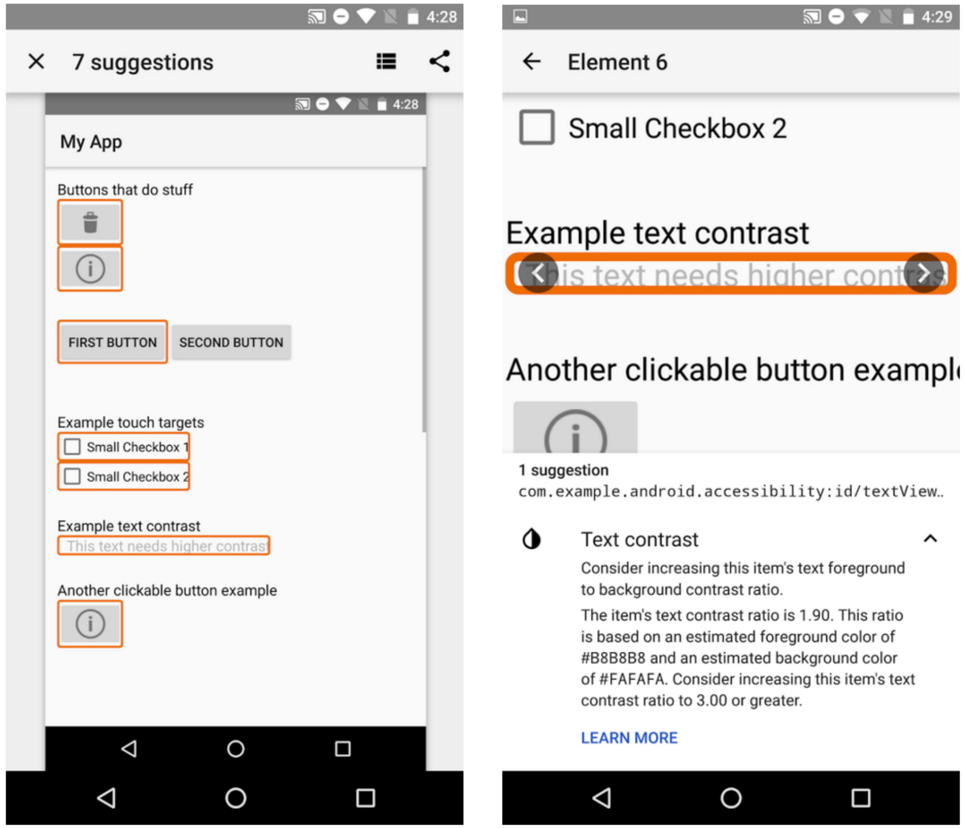
PROVIDING OPTIONS

INCLUSIVE SURVEYS

BECAUSE YOU WANT A RANDOM REPRESENTATIVE SAMPLE

Ensure Platform Compliance

Just ask



ArsTechnica

You want your research platform to be Web Content Accessibility Compliant.

- WCAG 2.0 A and AA (now in US)
- WCAG 2.1 A and AA (now in Europe, proactive in US)

You, The Last Line of Inclusivity

What you can do to make surveys WCAG compliant

- Make sure your colour contrasts are strong enough.
- Keep your text fields close to row labels.
- Have clear notifications and indicators.
- Use explicit navigation text.

Ask for WCAG Compliance

They won’t build for accessibility if the demand isn’t there

Photo by Camylla Battani on Unsplash

Keep It Simple

If you're not sure you can get fancy, don't

If you're not sure, keep to basic question formats.

Stay away from drag and drops, sliders, and any other fancy features which can to cause people using screen readers or other assistive devices problems.

Some platforms engineer their survey features to be both fancy and WCAG compliant. Ask to be absolutely certain this is the case.

Photo by Alireza Attari on Unsplash

INCLUSIVE STIMULI

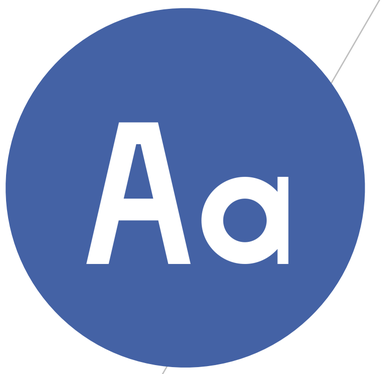
ASSETS EVERYONE CAN ASSESS

Text and Graphics Belong Together

The chocolate and peanut butter of stimuli

Text

Not everyone can read your words



Better Together

Graphics

Not everyone can see your pictures

Use Captions and Alt Text

Yes, again with the captions

Captions and Alt Text are a good idea, period.

They help for those with hearing issues, they’re great for people who are in situations where they need to keep their speakers on mute, and they help people who are visually impaired.

Watch Your Reading Levels

Written English is essentially a non-native language to people who grew up communicating in ASL.

GIVE THEM A HEADS UP

Some people are easily overstimulated.

Tell them ahead of time if they will be hearing or seeing something odd or unexpected.

Bentley University

Smashing Magazine

INCLUSIVE RECRUITING

HOW DO WE REACH THEM

DIY Options

Social media and advocacy orgs to the rescue!

TWITTER/INSTAGRAM

Try various hashtags.

- #a11y
- #disability
- #disabilityawareness
- #inclusion

FACEBOOK GROUPS

- Disability Support Group
- Hidden Disability
- Scope

REDDIT

- r/disability
- r/disabled
- r/blind
- r/autism
- r/cerebralpalsy

ADVOCACY GROUPS

- European Disability Alliance
- European Union of the Deaf
- European Blind Union
- Autism Europe
- Surveillance of Cerebral Palsy in Europe

Recruiter Options

Neither are perfect

Traditional Recruiters

Researchers are familiar with working with recruiters and how important the screener is to getting the kind of participants they want.

Recruiters may not be as familiar with the in's and out's of working with disabled participants.

Specialists

There are agencies which have databases of people with disabilities to participate in usability studies.

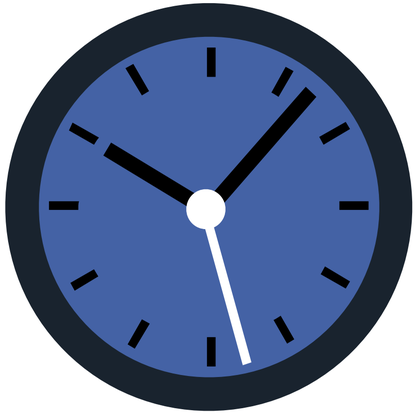
They usually recruit 6-people to participate in usability test featuring only disabled participants, but can be flexible for regular testing schedules.

They are typically more knowledgeable about getting the right participants, but not always in how to use them.

Scheduling the Session

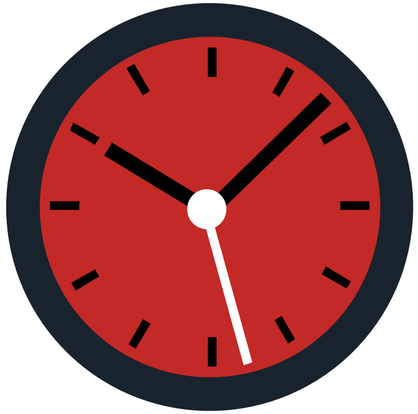
Timing is key

Save for Last



If you're only doing one session with a person or people with disabilities, save it for last.

Schedule by Severity



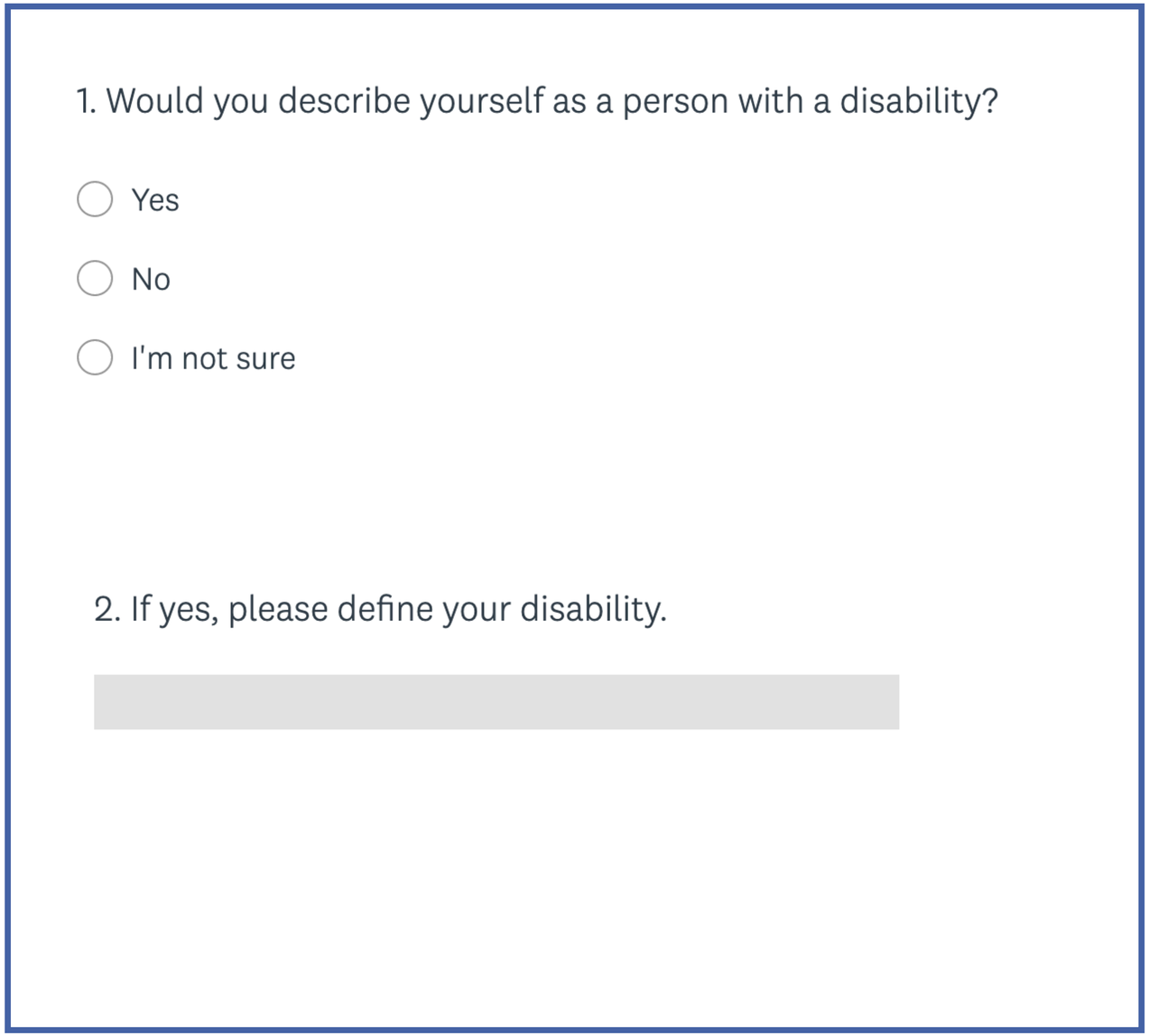
If you are doing multiple sessions with people with disabilities, try to save the more challenging interviews for last.

Trim Your Guide

You may have to trim down your guide to just the essential questions, making familiarity with the guide and project especially key.

Screeners

Allow for self-identification.



Screeners

Include a qualifying question.

Make sure the qualifying disabilities are relevant to the subject you're researching.

Send Your Instructions and Forms Early

Don’t use scanned documents. Take existing digital text files and either send them as Word or text-based emails or convert them to PDFs.

Allow for communication of consent which doesn’t require a signature.

Give people plenty of time to process and read your forms.

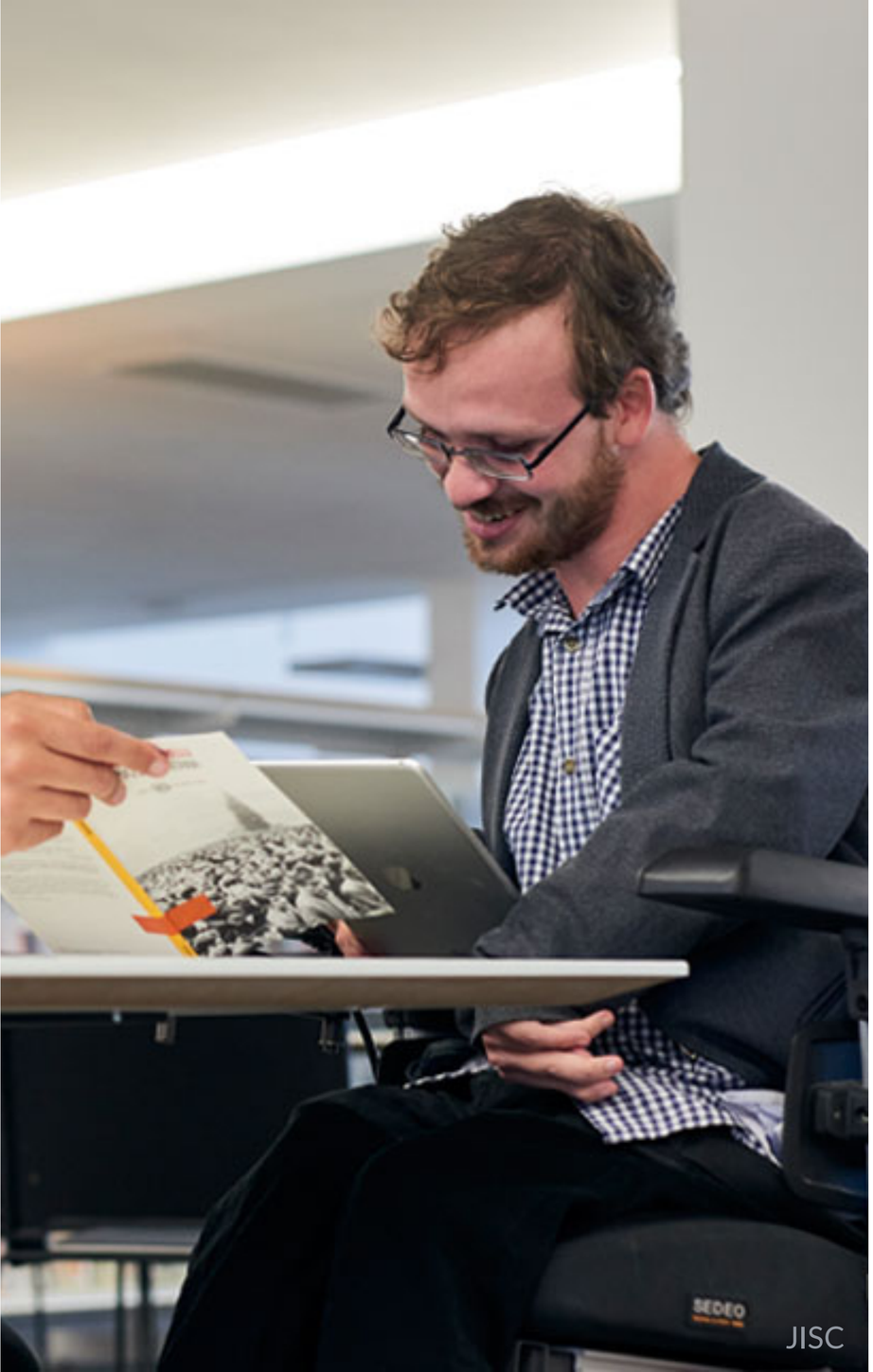
Provide Multiple Formats

Cover all your bases

WRITTEN

AUDIO

VISUAL



INCLUSIVE QUAL

BE COMPLIANT ONLINE AND OFFLINE

Device Compatibility

Make sure their assistive devices and settings, and yours, are compatible with the platform you'll be using.

And ensure the platform is WCAG compliant.

Coming to You

If they make the extra effort, so should you

HIGHER INCENTIVE

Expect to pay a higher incentive to the person with a disability because of the extra effort they have to make to be present.

CHECK THE FACILITY

Make sure the facility is accessible to the disabled and don't just take their word for it.

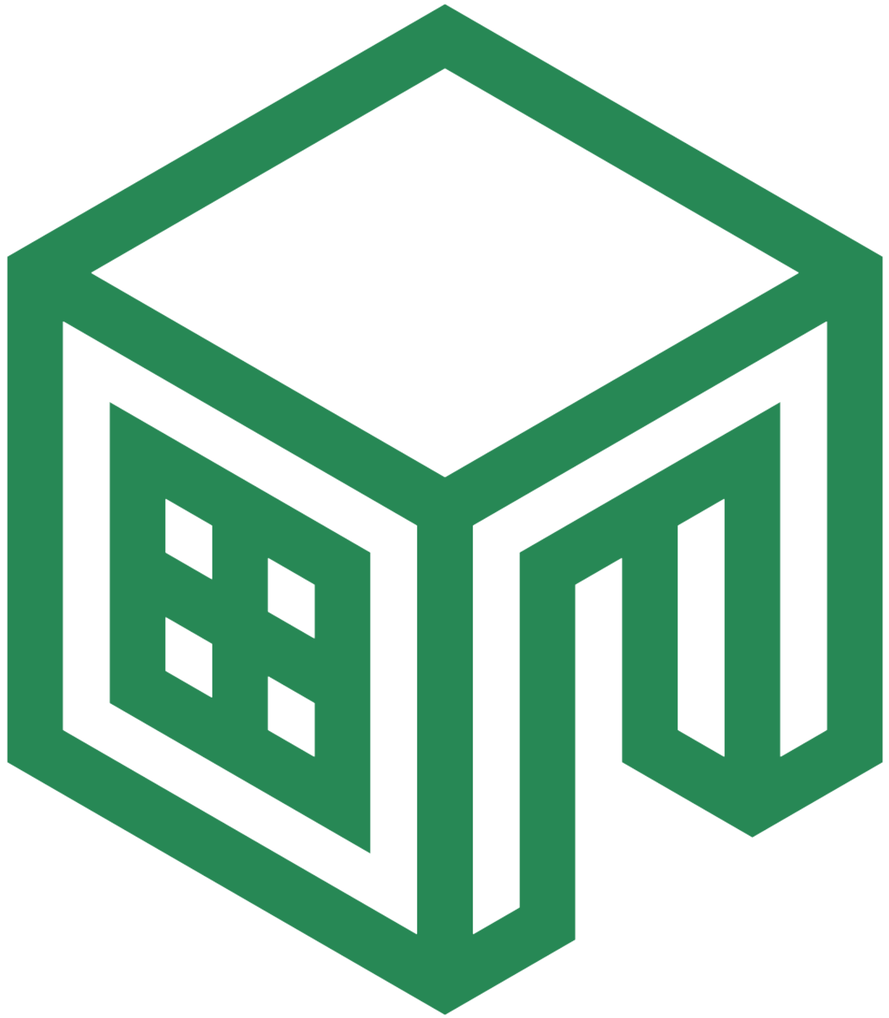
GO REMOTE

If you are doing IDI's try to arrange for one to be remote. It's just the path of least resistance.

The Room

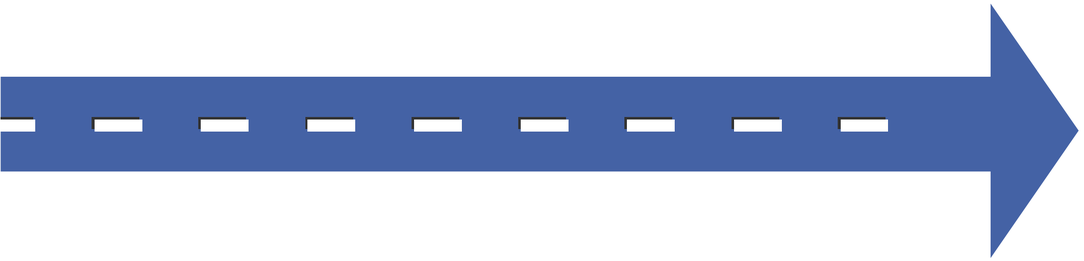
Make sure the table will accommodate a wheelchair and is height adjustable.

Doorways and hallways need to be wide enough.



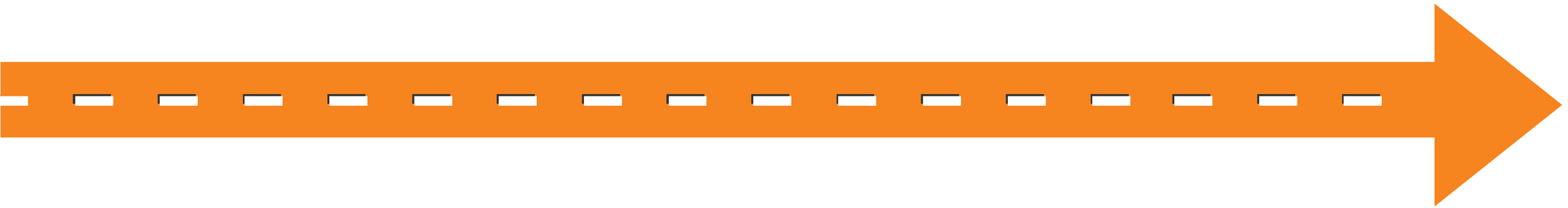
Give Detailed Arrival Instructions

Think through their journey



Know where and which bathroom accommodates people with disabilities.

Give them the best route to access elevators and automatic doors.



Identify the nearest disabled parking spots.

In Case of Emergency

Know where the accessible fire exits are at the facility and have a plan because this is research, stuff happens.

BE ACCOMMODATING

HOW CAN WE HELP?

Your Limitations

You can’t do everything

PERSONAL

Are there disabilities you can’t accommodate?

TECHNOLOGICAL

Is some of your tech screen reader incompatible?

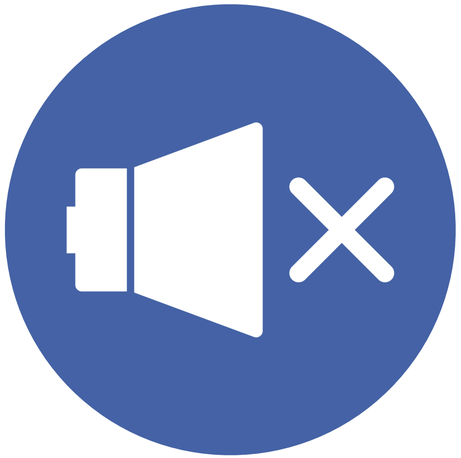
SITUATIONAL

Are any of the facilities inaccessible?

Photo by Joshua Hoehne on Unsplash

Their Limitations

They may not be able to do everything you ask



Communication Impairment

Shorten the discussion guide.

Visual Impairment

Find alternatives to visual stimuli.

Mobility Impairment

Offer to go to them.

Be a Good Host

Provide a disposable number to call or text you or the number of the facility.

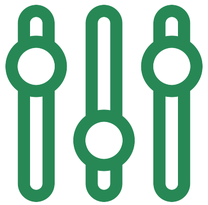
Be prepared to meet your participant at their drop off point and walk them into the the facility.

Rapport Building

Be more aware about your rapport building rituals.

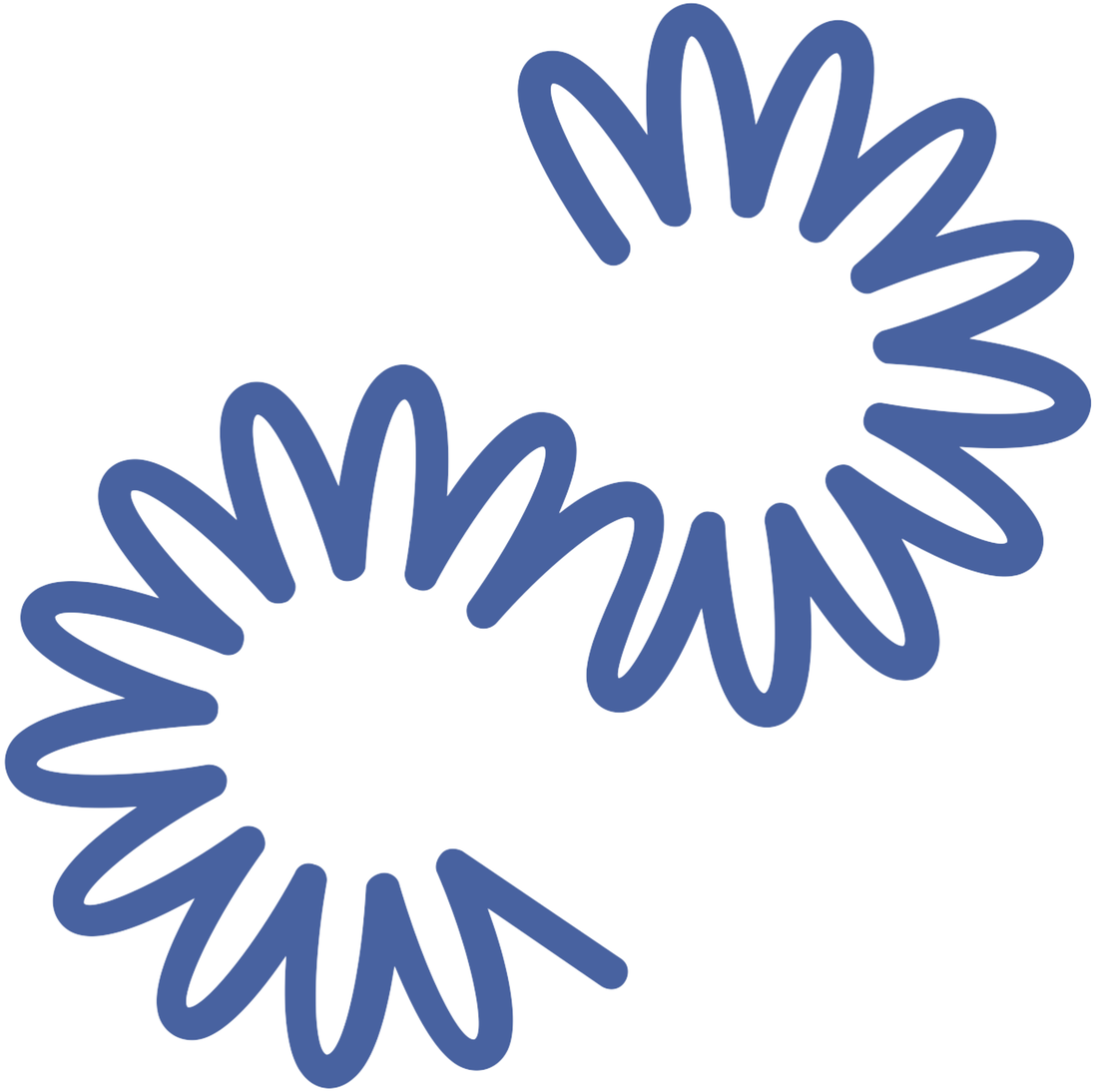
Find ways to talk about their disability without coming across as ableist.

Give them the opportunity to determine the terms of how their disability is discussed.



BE WILLING TO MODIFY

THERE IS NO ONE WAY



Be Flexible

Be prepared to make last minute changes and roll with the punches.

Have a Backup Plan

Prepare for multiple contingencies.

While having participants with disabilities bring their own devices is preferable, have something ready in case what they bring doesn't work with your setup.

- Download a trial version of a screen reader program and set the preferences to what they're most familiar with. You'll lose time, but you'll save the session.

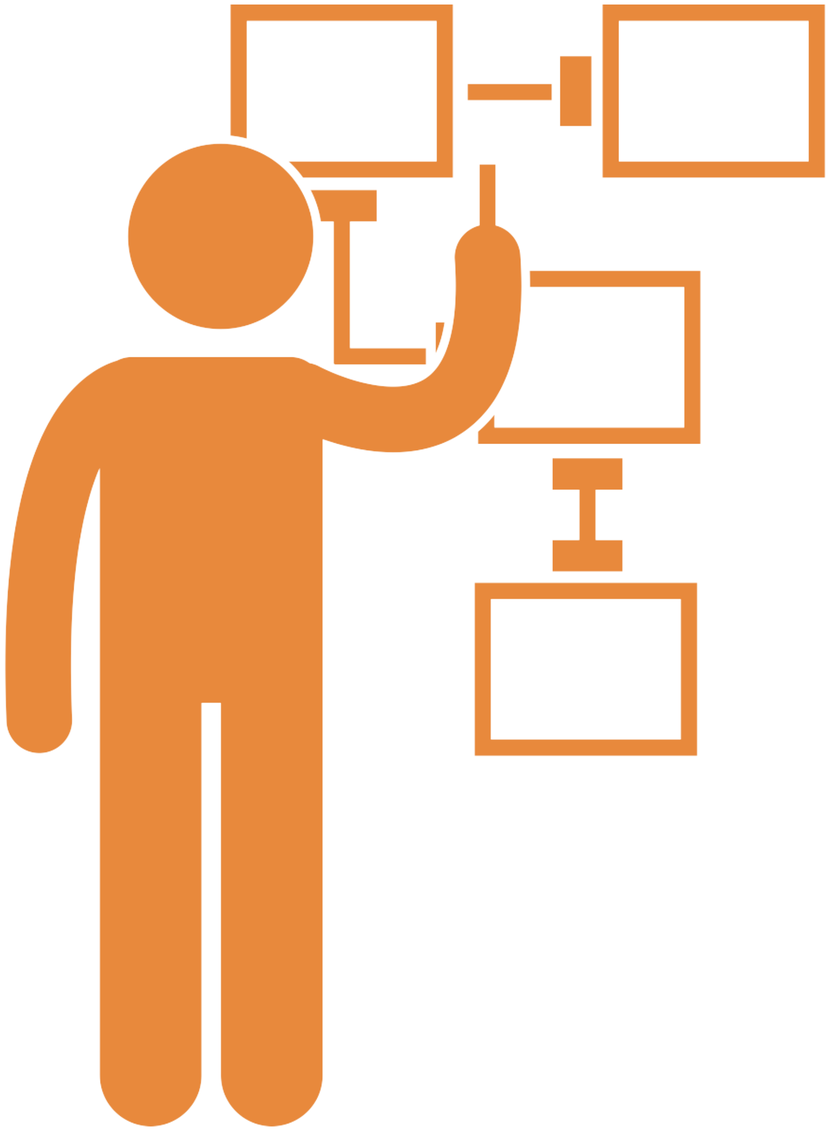


Photo by Jeremy Perkins on Unsplash

Allow for Multiple Breaks

Research sessions can be challenging for anyone. Be prepared to take breaks every now and then to not overwhelm your participant.

This is an Opportunity

THANK YOU

LAUREN ISAACSON

@CURIO_RESEARCH

CURIORESEARCH.NET

1% FOR THE PLANET — MEMBER —

Photo by Josh Appel on Unsplash