

Working with research participants with disabilities

16

16.1 INTRODUCTION

Chapter 15 talks about the approaches for and issues that arise when working with human participants in research. As the number of research projects involving users with disabilities grows, it is important also to examine the specific concepts, issues, and challenges of doing human-computer interaction (HCI) research involving users with various disabilities. Computer technology is now being used everywhere, by everyone, on a daily basis, for work, for pleasure, for communication, and for overall living. This includes users with perceptual disabilities (e.g., hearing and visual), motor disabilities (e.g., limited or no use of hands, arms, legs, or mouth), and cognitive/intellectual disabilities (whether lifelong impairments, such as Down syndrome and autism, impairments that develop over time, such as dementia and Alzheimer's disease, or event-based impairments, such as aphasia). It is important that users with disabilities be directly involved with research. When researchers don't directly involve people with disabilities, they often make assumptions, which wind up being stereotypes. For instance, one common assumption is that all people with disabilities use a form of assistive technology (an alternate or modified input or output device or approach), which is not true. As another example, some researchers may not know that Blind people can use power tools to build furniture and can also drive cars! Those are two examples of how assumptions can be wrong!

The grouping of “users with disabilities/impairments” is itself somewhat artificial. It encompasses lots of different individuals with different impairments, abilities, and strengths; all they may have in common is that they have the label “impairment” or “disability” attached to them. For instance, individuals who are Blind, and individuals who have Alzheimer's disease may have practically nothing in common. And people that are often grouped together in research may be exact opposites. For instance, in evaluating technologies for people with cognitive impairment, some researchers have grouped together young adults with Autism and Down syndrome, when they are often polar opposites in social skills, motor skills, and in some cases, intellectual skills. This is important to remember: you can't just group together people with different disabilities under that one large umbrella. While research on users with perceptual and motor disabilities has existed since the 1970s, only recently have researchers tackled the challenges of designing computer interfaces for users with cognitive disabilities (Lazar, 2007b) and only rarely have researchers worked with people having multiple impairments. It is important to note that in some countries, a

mental health challenge is also considered a disability under national laws, but that is outside the scope of this chapter (for more information on working with users with mental health issues, see [Johansson et al., 2015](#)).

It is also important to note that as people in general change their information consumption habits, they are often switching to interaction techniques primarily utilized by people with disabilities. For instance, captioning (which is known in much of Europe as subtitling) of video on television was used primarily for people who are Deaf or Hard of hearing, but as consumption patterns change, more of the general public (without disabilities) now get their news watching web-based video, and using the captioning, especially when they are in a location where they cannot play sound ([Crabb et al., 2015](#)). The same flexibility that allows digital information to work properly for someone with a disability will also allow for flexibility for someone without a disability who either has a situational impairment, or is just accessing information in a different way (e.g., from a smart phone) ([Lazar et al., 2015](#)). Many technologies that start out as assistive technology for a specific population of people with disabilities, such as audio books, speech recognition, and captioning, wind up later becoming popular among the general population ([Lazar et al., 2015](#)). So, for many reasons, researchers are interested in developing new accessibility techniques, and evaluating them with users both with and without disabilities. All products and interfaces should be designed for user diversity; disability should be a part of that!

It is important to note that different groups prefer different terminology. For instance, most communities of people with disabilities prefer people-first language (e.g., people WITH disabilities), however, two communities, Blind people and Deaf people, generally prefer language that is not people-first, and the Deaf community (capital D Deaf), meaning those who use sign language, and are a part of Deaf culture, do not consider themselves to have a disability, but consider themselves linguistically different. Also, the terminology for Autism has recently changed in the medical literature, so “Autism Spectrum Disorder” is preferred to a specific term like “Asperger's syndrome.” Different countries have different usage of terms, as well, so, for instance, in much of Europe, Blind=no residual vision, and visually impaired=low vision, but in the United States, Blind=no vision or low vision. Even the choice of using the term impairment versus disability can sometimes be controversial and there is no general agreement. While writing this chapter (and throughout the book), we strive to use the most respectful language, but acknowledge that what is considered most respectful by one community may not be considered the best choice by another community.

The goals of HCI research involving users with disabilities are the same as research with other users, to understand the phenomena surrounding computer interfaces and usage patterns. It's not sufficient just to take guidelines from the research on interface design for people with disabilities (such as the Web Content Accessibility Guidelines), and you can't just take proxy users (nonrepresentative users who do not meet the inclusion criteria) to represent the users with disabilities. You must work directly with users with disabilities.

This chapter describes how research involving people with disabilities, may differ from research with the general population. There are three areas which researchers need to pay careful attention to: (1) participants, (2) research methodology, and (3) logistics. Due to the diversity of disability, researchers need to pay careful attention to ensuring that the participants are the “right” participants for a study, meaning that the participants meet all of the inclusion criteria. Participant recruitment will likely be a challenge, and this chapter describes both methods for recruitment, as well as communication strategies. The overall research methods (experimental design, surveys, time diaries, case studies, etc.) are often the same as for research involving other users. However, the logistics of performing this type of research are generally what makes it different (e.g., where you perform your research, how you get participants to sign IRB forms, and how you pay users with disabilities for their participation). For people with cognitive disabilities, individual modifications to the research methods may sometimes need to be made (discussed in detail later in this chapter). There also may be factors in the research that you should be aware of, as they may bias your data in one direction or another. Due to these complex logistics, it is realistic to say that it may take more time to do research involving participants with disabilities. It is intensive, but you should do it anyway! And as mentioned earlier in this chapter, research that leads to improved interface and design experiences for people with disabilities may eventually lead to interfaces that are better for the general population!

16.2 PARTICIPANTS

16.2.1 INCLUSION CRITERIA

When recruiting users with disabilities for research, you must be very clear on the criteria for inclusion in the research study. Just saying that someone has a disability isn't sufficient, as the population of people with disabilities is not monolithic, and in fact, even within the population of people with the same specific disability, there is great diversity. [Table 16.1](#) displays the types of inclusion criteria that must be considered when doing HCI research involving people with disabilities. The goal of the research study, and the research methods involved, will help determine which of these inclusion criteria are relevant for the study. Some of the criteria simply relate to the representativeness of participants. So, for instance, people with a specific disability who are also employed in a certain field (e.g., people who are Deaf or Blind and also are lawyers). Some inclusion criteria relate to history of, or severity of a disability (e.g., people who have been Blind since birth versus people who lost vision later in life). Other inclusion criteria relate to experience and frequency of using a technology. Often, new users of assistive technology, without years of experience, or who do not utilize the technology on a frequent basis, will not be familiar enough with the technology to effectively use it in any type of research project. Other inclusion criteria may relate to communication methods: do your participants need to be fluent in sign language? Or in Braille? Keep in mind that it is estimated that only 10%–20%

Table 16.1 Typical Types of Inclusion Criteria When Doing HCI Research Involving People With Disabilities

Inclusion Criteria
<i>Technology</i> <ul style="list-style-type: none">– Which assistive technologies do the participants use or not use?– How many years of experience do participants have using a specific technology (assistive or otherwise)?– How many hours a week do participants utilize a specific technology?– Do participants have experience with certain brands of assistive technology, or do they use it in certain combinations?
<i>Education</i> <ul style="list-style-type: none">– What level of education is required? Secondary school (high school)? An undergraduate (bachelor's) degree? A graduate degree?– Is formal training in computer usage (e.g. software applications, OS, keyboarding) required for participation?
<i>Employment</i> <ul style="list-style-type: none">– Must the participants be employed in certain job roles?– Must the participants be involved in paid employment?
<i>Disability</i> <ul style="list-style-type: none">– Is there a certain medical diagnosis that is required? (e.g., Trisomy 21 or Mosaic Down Syndrome?)– Is there a certain severity of a disability required for participation (e.g., no residual vision or some vision?)– Can participants be allowed to use aids (e.g., are people who use cochlear implants acceptable for the research study?)– How long must participants have had the disability (e.g., born Blind or lost vision as an adult?)– Have participants previously participated in rehabilitation training activities (e.g., such as orientation and mobility for Blind people?)– Do participants use any electronic prostheses?
<i>Communication</i> <ul style="list-style-type: none">– Must participants be able to independently communicate?– Must participants be fluent in sign language or Braille?

of Blind adults are fluent in Braille (which tends to surprise most people who don't work regularly in the blindness community).

It is important to note that, it may be hard to get detailed information about the medical status of someone with a disability (e.g., their cognitive level, their visual acuity, or range of motion), because of sensitivity involved in sharing personal health data, or national laws that limit the sharing of health data. However, there can be substitutes, described in assistive technology terms, for ensuring the same qualities in participants. For instance, rather than stipulating the visual acuity data, participants can be recruited by asking for those who are “screen reader users, unable to use screen magnification” meaning that there is close to no residual vision. Or asking about the use of tools such as magnifiers and closed-circuit television (CCTV),

indicates that someone is low vision (Zhao et al., 2015). Sometimes, automated data collection of typing speed, or pointing performance, can help in measuring motor performance (Hurst et al., 2013). Furthermore, it is important to note that due to policies in some countries, people with certain disabilities may not be allowed to earn over a certain amount of money or they will lose their government benefits, so there are people who are employed in respectable positions, but are not being fully paid, or people who are underemployed, because they will lose their health benefits if they are fully employed. This may also mean that participants, in limited circumstances, may not be able to accept large payments for participation in a research study.

16.2.2 DIFFERING LEVELS OF ABILITY

Ability levels may vary widely among users with a specific disability (Jaeger, 2009). Assumptions should never be made, for instance, about “what users with aphasia are capable of.” Since many disabilities are due to underlying medical or health causes, the severity of the impairment will vary among different users. Most impairments are not binary, that you either have them or don't. People can have partial impairments (such as partial hearing or visual impairment). People can have varying severity of impact (for instance, mild, moderate, or severe Aphasia, Alzheimer's disease, or dementia). So for instance, if Aphasia was caused by a stroke or head injury, the severity of the stroke or head injury, as well as the time elapsed from the Aphasia-causing event, can both impact on the severity (Miller et al., 2013). Even impairments that at first seem to be very clear and binary are actually not. For instance, there are different types of amnesia, based on what type of memory capability has been lost. While trisomy Down syndrome is the most common form (95%), there is another type of Down syndrome, called “mosaic Down syndrome,” that is much rarer, but generally has a lesser impact on cognitive performance. Autism Spectrum Disorders even note the diversity (“spectrum”) in their name. In all of these situations it is important to fully understand the nature and diversity of the population, by consulting experts in that specific impairment. In addition, standardized tests that measure the severity of the impairment can be very useful, as long as they are properly conducted and interpreted (Moffatt et al., 2004). Not only does the severity of the impairment influence interface design, but even for people at the same level of impairment, there are a number of other factors that influence performance on interface-related tasks, including: confidence, self-efficacy, and previous experience with using computers. The results are not always what they seem and it takes a lot of experience with a specific user population to understand this.

For instance, research tasks that might take user A only 1 hour might take user B 3.5 hours. In a typical population without disabilities, this would lead the researcher to believe that either users B's skills and task performance are lower, or maybe there is a problem with the equipment that user B is utilizing (e.g., it is older equipment or slower network connections). However, this would not necessarily hold true for populations with disabilities. For instance, newer users of a certain application or tool (such as head tracking) might be satisfied with completing a series of tasks

in 3.5 hours. This same amount of time might be frustrating to someone who has utilized the equipment for years. Each user with a disability (or a combination of disabilities) is a unique individual, with a unique performance speed that they alone consider to be their average “default speed.” The “default speed” should be taken into consideration to determine individual usability. However, the “default speed” can also be a complication when trying to compare the performance of a group of users with a specific disability. For instance, typical data input and output speeds vary more greatly for users with disabilities than for the general user population. As an example, Blind users listen to their screen readers (e.g., JAWS, VoiceOver, and Window-Eyes) at varying rates, and tend to think that any speed that is not their pre-set speed is either too fast or too slow. In experimental studies with Blind users, you may want to remove the potential confounding factor of having various screen reader speeds in the mix by using one screen reader speed for every participant, although this may frustrate the individuals who participate. Alternatively, you might check the speech rate that each user has set on their computer, but note that they will not be comparable across different screen reader brands.

In another example of the complexity of user differences within a specific impairment population, for a screen reader user who listens to the screen reader at a very rapid rate, they may be frustrated if a task takes more than 5 minutes to complete. Another user, who listens to the screen reader at a much slower speed, may be very satisfied if the same task takes 20 minutes to complete. Their personal expectations of performance may not always be obvious to the researcher and this may be hard to measure. Experience with the computer and confidence may also play a role. For instance, imagine three Blind users, all of whom are attempting the same task. User A may give up after 2 minutes of attempting the task, because they know that they typically can only find information using four different navigation methods, and once they have attempted all four navigation methods, it is pointless to continue, as they are confident that they would not be able to use any other method and succeed. User B may also give up after 2 minutes, but because they have low confidence. They are not confident in their abilities and think it is unlikely that they will be able to complete a task. User C does not give up, even after 45 minutes of attempting a task. While the computing skill set of user C might be high or low, they are confident in their abilities, and they repeatedly say, “I am not a quitter. I will keep going until I am able to complete the task.” The authors of this book have personally witnessed all three behaviors. In this example, time is not directly correlated to technical experience or confidence, but rather, is influenced by both.

Experience can also play a factor in how people with disabilities perceive the user experience. For instance, Blind users often do not subjectively rate interface problems as being as bad as the objective performance ratings document (Trewin et al., 2015). One possible reason for this is that their previous experience with technology includes so many barriers to be overcome, that their expectations for their interaction experience are a low baseline, and interface problems may not be perceived as bad as they really are (Trewin et al., 2015). For instance, the research documents that Blind users may generally have a positive outlook (Trewin et al., 2015), and interface

barriers may only impact on mood when it interferes with work (Lazar et al., 2006). Due to how participant baselines and expectations may differ, it is important that, if researchers use the terms “low accessibility” and “high accessibility” at any point interacting with participants, the researchers should be clear to define what the working definitions of those terms are. Does high accessibility mean true ease of use, or simply compliance with international technical standards such as the Web Content Accessibility Guidelines (WCAG) 2.0? Does low accessibility mean that a task can technically be accomplished but it is hard to use, or does low accessibility equate to inaccessible because there are so many barriers which make task completion impossible? Use of terminology must be clear.

Given that users with disabilities are really a mosaic of different communities with different needs, it is sometimes important to test an interface with either multiple groups, or a combination of users with and without disabilities. There are generally two approaches for developing interfaces for users with disabilities (Lazar, 2007a):

- Try to make an interface (for a website, digital library, application, or operating system) that works well for a majority of users (both with and without disabilities). Usually, this is the scenario where all users have the same end task goals (such as accessing an article or purchasing a song online), and they are simply utilizing alternative input or output devices (Slatin and Rush, 2003). This could be called the universal design approach.
- Design an interface that is optimized for a specific user group. This is the approach that tends to be used for people with severe cognitive disability, including children with autism and adults with Alzheimer's disease or aphasia (Cohene et al., 2005; Moffatt et al., 2004; Tartaro, 2007). The needs of the population are so specific, that the interface, and the corresponding task scenarios and applications, are so focused on the specific needs of the user population that they are unlikely to meet the needs of other populations. This is often used for Augmentative and Alternative communication devices, where the device is designed to meet the needs of one user or a group of users.

16.2.3 RECRUITMENT OF PARTICIPANTS WITH DISABILITIES

One of the greatest challenges of doing research involving users with disabilities is the recruitment of participants. There are a number of complex aspects of recruiting participants with disabilities into your research study. You can't just place signs in the computer science department or on campus saying, “we want users with spinal cord injuries to take part in our research study,” as there are often not a sufficient number of individuals with specific disabilities on university campuses. The same holds true for research labs at corporations and government agencies. It's not likely that there are a sufficient number of people with the specific disabilities at your company or government agency (unless you work for a very large company or government agency). Certain offices at a university or a company (e.g., the Disability Student Services office, or the Compliance Office) may have a list of all people with disabilities in an organization, but you can expect that they will be reluctant to share

that information with you, and according to the laws of some countries, it may be illegal to share that information. Also, depending on the national or regional laws of a country, an individual may not be required to identify that they have a disability. So the concept of being presented with a list of all people with disabilities within an organization, is simply not a realistic concept.

Some academic departments (often in Psychology and Education) have “pools” of potential participants for research studies, but again, they rarely will have a sufficient number of people with disabilities in those pools. The often-used (but often-not-appropriate) practice of recruiting students in computer science for research studies, will not help you reach this goal. When there are a few people with disabilities within an organization, they are often repeatedly asked to participate in every study, leading to those users becoming very experienced in research ([Dee and Hanson, 2014](#)). Some researchers choose to use “simulated impairments,” where people without disabilities, say, are blindfolded or have their hands tied behind their back, but this should not be done, even for portions of a study. There are limited situations where using proxy users are appropriate, and they are discussed in later sections (specifically, [Section 16.2.6](#)).

PARTNERING WITH ADVOCACY GROUPS

The best way to recruit users with disabilities is usually to partner with a community-based group that focuses on the disability of interest to the research. Most people with disabilities have some sort of organization, support group, or coordination point. For instance, there are organizations of people with visual and hearing impairments, organizations of people with spinal cord injuries, and organizations of people with Alzheimer's disease. In cases where the disabilities impact the ability to live an independent life, these organizations often include caregivers and family members. It is usually good to approach these organizations for help in recruiting users. However, simply saying, “we want to do some research, and we need your help in recruiting users” is not sufficient, and it is hard to establish immediate trust ([Feng et al., 2005](#)). If you really care about these user populations, then you need to become involved with the community-based group for the long term. Most of these organizations get multiple requests for help, and they may be leery of “drive-by research,” where you ask for their help, do the research, and then never show up or contact them again. When people feel a sense of reciprocity, they are more likely to participate in research ([Dee and Hanson, 2014](#)).

Some organizations are geographically based and you may want to contact their national offices. For instance, the Royal National Institute of Blind People in the United Kingdom and the National Federation of the Blind in the United States are leading organizations for Blind individuals. The

National Association of the Deaf, the Alexander Graham Bell Association for the Deaf and Hard of Hearing, the Alzheimer's Association, the National Down Syndrome Congress, National Spinal Cord Injury Association, and the Autistic Self Advocacy Network, rank among some of the better-known groups. While national organizations are common, other organizations may work at the grassroots, with local city-based groups that do not coordinate with each other. If possible, you should become a part of these organizations: go to their meetings, meet people, get involved in their community, and take part in fundraisers. If there is a regional or national convention, it is important to attend that gathering. At these gatherings, it is possible to better understand the logistics and challenges involved for that population, which can help with the planned research in the future. But it isn't sufficient to go to the meetings just to learn about issues such as Braille handouts or physical room limitations for individuals in wheelchairs. The end goal should not simply be to further your research, but to further the cause of these individuals and their quality of life. Your research is simply a piece of that long-term goal. As such, your partnership needs to be a two-way street. If you are asking for their help, then they should be able to expect your help. You should find a way to compensate the organization for their assistance to you. When your research is complete, you should make sure that the organization receives copies of any final reports. Rehabilitation centers that are often sponsored by local governments or industry, provide training and modifications to help adults with certain impairments move into the workforce. These organizations can often be sources of participants for research.

If you are working with a community-based organization that specializes in a certain impairment, the goal of your research is to further their cause and improve the quality of life for individuals with the specific impairment by improving understanding of HCI issues for the user population. If the only goal you have is to further your own professional career, with little concern for the needs of the population, look elsewhere. Working with users with disabilities is a long-term, emotional, involved process, with great societal benefit and long-term payoffs in the quality of life for individuals. Expect that the organizations involved will come to count on you and consider you a part of their cause. Invest in the long term or get out of the game. <End of sermon>.

16.2.4 COMMUNICATING WITH PEOPLE WHO ARE DEAF OR HARD OF HEARING

If a research study involves participants who are Deaf or Hard of hearing, then it is important to ascertain whether the participants will need sign language interpretation. It is possible that other forms of accommodation may be necessary (e.g., oral interpretation, induction/hearing loops), but sign language is a

necessary accommodation for people who are Deaf (meaning that they are a part of Deaf culture and primarily use sign language). It is important to note that people who identify as Hard of hearing may not be sign language users.

If multiple researchers are fluent in the relevant sign language, that may be sufficient, but often, it may be necessary to bring in sign language interpreters, to ensure full communication with your participants. For instance, [Shiver and Wolfe \(2015\)](#) brought in sign language facilitators (who were themselves Deaf), to lead interviews with Deaf participants via videophone. Typically, sign language interpreters are brought in as pairs (e.g., so that they can substitute for each other and take breaks), but if there are multiple Deaf people taking part in multiple conversations at the same time, multiple interpreters may be necessary. Or if there is a presentation that will be made to a large number of people as a part of the research, perhaps real-time captioning (CART) might be a useful addition to sign language interpretation. If teleconferencing or telepresence will be involved in the research, and the group is mixed both in terms of hearing and in terms of physical location, we suggest that the reader consult ([Vogler et al., 2013](#)) for detailed advice. It is important to note that there are many different national sign languages (e.g., American Sign Language, Brazilian Sign Language, Mexican Sign Language, Norwegian Sign Language, etc.) which may be relevant depending on the participants and geographic location. However, it is NOT sufficient to say that researchers can just write messages on paper and text messages to their Deaf participants. That would be insulting and rude, to ask for the participation of Deaf participants, without ensuring that sign language interpreters will be present.

16.2.5 COMMUNICATING WITH PEOPLE WITH MODERATE TO SEVERE SPEECH IMPAIRMENTS

It is important to consider that some participants may have moderate to severe speech impairments and be unable to communicate orally (note that we are not including people who can communicate using sign language in this classification). Some of these people may simply be using an Augmentative and alternative communication (AAC) device. AAC devices are primarily used to allow people with communication challenges, to communicate more effectively using selection devices and computer-synthesized speech output. It is important to determine what the expressive language skills are, of potential participants, and then plan for multiple possible approaches for communication. Plan for participants to use AAC, and also think about whether more of the data collection should be in written format, where participants can fill out surveys or time diaries over a period of time, rather than be rushed to fill out text on the spot ([Mahmud and Martens, 2015](#)).

Be aware that because someone has challenges with speaking or expressive language skills, that does not necessarily mean that they have challenges with understanding spoken language (receptive language skills). In their study of an email application designed specifically for people with Aphasia, [Mahmud and Martens \(2015\)](#) note that there are two general kinds of Aphasia: nonfluent Aphasia and fluent Aphasia. People with fluent Aphasia have trouble with language comprehension,

whereas people with nonfluent Aphasia (the focus of their study) are generally able to understand verbal communication.

16.2.6 PROXY USERS

In the past, some researchers would use “proxy users,” where individuals without disabilities would represent individuals with disabilities during design or research. This could include people with no connection to the disability and people with some knowledge of the disability. Examples of people with no connection to the disability include blindfolding people who can see, or tying people's hands behind their back to simulate users with motor impairments (Sears and Hanson, 2012). These “simulations” or “temporarily impaired users” are generally not encouraged for any type of research as, over time, users with perceptual or motor impairments learn to compensate by becoming more reliant upon their other senses or body parts (Sears and Hanson, 2012). Someone who is Blind has learned to rely more on their hearing than someone who can see. Even if the users of interest and users without any disabilities are considered to have equal skill in some area (for instance, good quality speech), the impairment makes users perceive the technology differently. So, for example, it is inappropriate to test speech-recognition solutions for users with spinal cord injuries, by using users without any impairment, based on the claim that they have similar quality speech (Feng et al., 2005). Since users often compare a new technology to a previously used technology or option, the comparisons are very different. Domain experience also is an important factor. For instance, in testing technologies for Blind people to drive cars using nonvisual techniques, it would be inappropriate to have participants who can see but are wearing blindfolds, as they have, in many cases, years of experience driving cars (Sucu and Folmer, 2014).

There are some limited situations where it may be appropriate to use people who are familiar with the users and impairments to represent the users themselves. These are generally situations where users are unable to communicate, or are unable to process information due to their impairment. For instance, one study used speech language pathologists who worked closely with individuals with aphasia, instead of the actual users themselves, to get an understanding of user needs (Boyd-Graber et al., 2006). In another study, caregivers and family members were used as the primary information sources for designing technology for individuals with Alzheimer's disease (Cohene et al., 2005).

Another model of proxy users is to use pairs of users and their caregivers or therapists. For instance, in a study about designing walking technology for people with Dementia, pairs of people with dementia, and their primary family caregivers, were involved in the research (Holbø et al., 2013). In another study related to tools for therapy relating to childhood apraxia of speech, both children with apraxia of speech and their speech therapists, were paired up for the research (Parnandi et al., 2013). In some cases, children answered subjective questions, but in other cases, since the children were 3–7 years old and had childhood apraxia of speech, their parents answered for them. Another situation where proxy users might be appropriate is when a

specific application or tool is being developed and it is undergoing multiple iterations before a proof-of-concept is complete. If users with the specific disability would not be available to take part in all stages and all iterations of design, then proxy users might be suitable in limited stages and limited circumstances, for preliminary evaluation, although this is not ideal. They should closely be followed up by evaluations with users who actually are representative and do have the relevant disability. Some authors have gone as far as to say that all studies being published in archival venues must have representative users ([Sears and Hanson, 2012](#)).

Note that, even with a cognitive or motor impairment, many participants can communicate by using some form of AAC device (as described in earlier sections). You should never use proxy users when participants can communicate but the researchers don't "speak their language" (such as people who are Deaf and use sign language or Deaf-blind users who use Braille or finger-spelling), or the participants utilize AAC.

16.3 METHODOLOGICAL CONSIDERATIONS

In general, the research methods described in other chapters of this book can be utilized in any research involving people with disabilities. However, when doing research involving people with disabilities, there are a number of methodological issues that a researcher should consider when planning for data collection.

In experimental research with the general population of users, it is often expected that a research study would have a minimum of 30–40 users, to be considered valid (see [Chapters 2–4](#) for more information on sample sizes in experimental design and [Chapter 5](#) for more information on sample sizes in survey research). These expectations may not be realistic for users with disabilities, as it might be impossible to get access to so many users in one geographic area with a specific disability. The generally accepted approaches for dealing with the issue of access to appropriate participants for research focusing on users with disabilities are: small sample sizes, distributed research, and in-depth case studies. Choosing the most appropriate approach will depend on the nature of the research questions. For instance, highly controlled studies will often use small sample sizes or in-depth case studies where researchers can be physically present with the participants. Research of a more exploratory nature (with fewer controls) can use distributed research.

16.3.1 SMALL SAMPLE SIZES

For research focusing on users with disabilities, it is generally acceptable to have 5–10 users with a specific disability take part in a study. This is due to a number of reasons. For instance, it may be hard to find participants with disabilities that meet all of the inclusion criteria discussed earlier in the chapter (employment, education, technical expertise). Or it may be hard to find people with a specific disability in a given geographical area (e.g., Mosaic Down Syndrome) or people with a certain disability where they are still able to take part in the research (e.g., ALS). For example,

in the recent proceedings of the ASSETS conference (well accepted as a high-quality conference on this topic), many of the research studies in which users with disabilities had to be physically present to take part in the research had 15 or fewer individuals taking part in the research.

Because of the small number of participants with disabilities who often take part, this means that if a classic experimental design is used, there will often be no more than one control group and one treatment group, as the number of participants does not allow for statistical tests for multiple treatment groups, so repeated measures designs tend to be used if experimental design is used at all (see [Chapters 2–4](#) for more information on experimental design). Because of the sample size issue, experimental design is used less often in research involving people with disabilities, though it can be used. One common approach is to have a group of participants with a specific disability, and a group of participants without a disability as the control group ([Sears and Hanson, 2012](#)). Care needs to be taken in justification and interpretation of results in these experimental designs; for instance, if demographic data does not identify significant differences between the groups (e.g., in age or education), that does not mean that the groups can be considered equivalent ([Sears and Hanson, 2012](#)). Experimental design methodologies involving people with disabilities can be done. However, due to the sample size issue, research involving people with disabilities, is often exploratory (rather than strict experimental design), a hybrid of quantitative and qualitative research, or primarily qualitative. There are not many users involved, but the data collection is certainly deep. For example, [Mcintyre and Hanson \(2014\)](#) describe how they used a combination of in-person interviews involving researchers and Blind individuals, before and after a navigation task within a building, while a digital recorder, not researchers, recorded data as 10 Blind and low vision participants were performing the navigation task within the building.

16.3.2 DISTRIBUTED RESEARCH

If not enough participants with disabilities, who meet the inclusion criteria, are available in a local area, another approach is to do distributed research, where the users do the research in their own home or office, without researchers present, and data is collected via time diaries, surveys, keystroke logging, or another method. Remote data collection generally allows for higher numbers of users (100 users or more) to take part in the research, because you can draw from potential participants over a much wider geographical area. In addition, a number of the challenges discussed later in the chapter (such as scheduling and transportation) may not be present for distributed research. However, there are drawbacks to remote data collection (see [Chapters 10 and 14](#)). It lowers the control that the researchers have over the study, and generally, the amount and richness of data collection will not be comparable to a research study done in-person ([Petrie et al., 2006](#)). Furthermore, it may not be possible to ascertain much detail about the specific technical environment utilized by the participant, when the data is collected remotely ([Petrie et al., 2006](#)). If software needs to be installed remotely, in a technology environment that researchers do not have

direct access to, and may not be 100% aware of the configurations, this may pose a logistical problem. One hybrid approach is to have participants come to a centralized location to get trained on how to do the data collection, and then to remotely collect data and send the data results back to the researchers (Petrie et al., 2006).

There are multiple ways to do distributed research. For instance, one approach is to go for a high number of participants, using a standard data collection method, such as time diaries or surveys, which don't require researchers to be present. Lazar et al. (2007) describe how 100 Blind participants took part in a time diary study to examine what frustrating situations occur on the web, how they respond, and how it impacts on their work and time lost. Rich text format files were provided, with specified spaces for participants to enter their data. Surveys are often used for distributed research, because of the ease in getting a lot of responses. Feng et al. (2008) collected 561 surveys from parents, relating to the computer usage of their children with Down syndrome. Wentz and Lazar (2016) collected 150 surveys from Blind users, about the challenges they face when software updates or website redesigns are inaccessible. Porter and Kientz (2013) collected 55 surveys from people with various disabilities (primarily motor disabilities, but also visual, hearing, and cognitive), about the barriers that they faced in video gaming. Apart from surveys and time diaries, participants can be asked to perform tasks remotely on the web, with data being collected either via a remote usability testing application, video conferencing, or Javascript inserted into web pages. As an example, Bigham and Cavender (2009) had 89 Blind participants attempting to perform a series of tasks on audio CAPTCHAs, with data collected remotely. Another approach to distributed research is to analyze publicly available information (such as tweets), because although you may not be able to determine which individuals have disabilities, you can determine which tweets are about the topic of access for people with disabilities (Brady and Bigham, 2014).

Another approach to distributed research is to combine a remote data collection method, with interviews (either in-person or distributed). Shinohara and Wobbrock (2016) had 14 participants who were Blind, low vision, or Deaf and hard of hearing take part in a diary study related to social comfort of using assistive technologies, (which isn't a large sample), but which resulted in 97 diary entries and then 12 follow-up interviews done, mostly by phone.

16.3.3 IN-DEPTH CASE STUDIES

Yet another approach is to do in-depth case studies, in which fewer users (say, between three and 10) take part in a more intensive way. These studies might involve data collection over several days, or users being trained, or longitudinal studies. This is most appropriate when data cannot be appropriately collected in a short amount of time (say, 2–3 hours). For instance, for many complex software applications or devices, users really do need a period of training, as well as time to familiarize themselves with the tool. A 2-day period of research for each user can be seen as a minimum for a case study. Ideally, longitudinal studies would examine how users

adapt to and utilize a new application over 3–6 months, although this is not always possible. There are multiple examples of how to do more in-depth and longitudinal case studies. For instance, [Montague et al. \(2014\)](#) describe their study, involving nine users with motor impairments (primarily due to Parkinson's disease), who utilized a mobile device for a period of 4 weeks while data was being collected. [Buehler et al. \(2015\)](#) describe a case study, over 11 weeks of training an individual with an intellectual disability and short-term memory loss, to independently design and print 3D models. [Mahmud and Martens \(2015\)](#) describe a study where people with Aphasia learn to use an email tool over a 3-month long period.

In some cases, a case study can provide an in-depth examination of only one person with a disability (see the sidebar in [Chapter 7](#), relating to a case study of Sara). There can also be interesting twists in doing case studies. For instance, Torsten Felzer, who recently passed away, was a dedicated member of the community of researchers interested in accessibility. He himself had Friedreich's Ataxia, a neuromuscular disease, and as a researcher, he documented his own case study, of challenges that he faced, and new approaches that he tried, and which approaches worked, and how that changed over time as his disease progressed ([Felzer and Rinderknecht, 2013](#)).

16.3.4 CONSISTENT TECHNICAL ENVIRONMENT OR BEST CASE SCENARIO?

If your research study involves having people with disabilities interacting with a software application, operating system, or web site, one of the important methodological considerations is whether to use a standard technical configuration for all participants taking part, or to allow them to utilize their own technical setup. There are benefits and drawbacks to both situations. Many users with disabilities have spent time creating the optimal configuration for their usage. Because various assistive technologies (such as screen readers, Braille displays, and alternate input and output devices) are involved, sometimes it takes practice and tweaking to figure out the optimal configuration (which web browsers, operating systems, and which specific settings) that makes everything work together. Furthermore, there are also settings that are optimized for that specific user (e.g., speed of screen reader, level of magnification, color contrast, etc.). So the user likely has their own technical environment customized and optimized for performance. This may mean, for instance, that some component of the configuration (e.g., an operating system or application) is not the latest version.

In some cases, such as users testing a single software application or web site, or research focusing more on user behavior or performance, it may be possible to allow all users to utilize their own technical environment. There are benefits and drawbacks to doing this. The benefit of allowing users to utilize their own assistive technology and computer setup (with the associated settings), is that the data collected will be under the “best case scenario.” This scenario will show users at what is most likely their peak performance level. Any usability problems identified will probably not be overestimated and will likely be conservative. Such an approach helps address

doubters who will look at data and say, “the user experience isn't really this bad,” as the problems reported will be as conservative as possible. Also, allowing users to use their own technical environment makes it more likely that, as only one or two new technical components are introduced to them, that you would have isolated the impact of the new items. In an extreme situation, if users were presented with new hardware, OS, application, and assistive technology at the same time, it would be hard to isolate the impact of any of the individual technologies.

However, this situation of allowing users to utilize their own technical environment may not be possible if part of what is being evaluated in research is a new set of technical configurations or applications. Another reason why allowing users to utilize their own technical environment may not be possible, is because the research involves a strict experimental design, and the technical environment needs to be controlled for. It would be a confounding factor in experimental design, if each user utilized a different technical environment. For instance, if a series of Deaf users had different screen sizes for reading the captioning, or Blind users were using different screen readers and listening at different rates of speech, these factors would clearly not be controlled for in an experimental design. It is important for researchers to plan ahead and consider if they want to allow users to utilize their own technical environment, or if they want to control the technical environment and make it consistent.

16.3.5 INTERVENTIONS

Researchers should consider when interventions, during data collection, may be appropriate and how they should be documented. Interventions, as described in the chapter on usability testing, are when there is an interface barrier that users are presented with, which does not allow the user to continue in the interface. These barriers are often accessibility barriers. So, for instance, if a login screen or an interface screen is inaccessible, it means that a participant with a disability may not be able to continue to use the rest of the web site or application. Generally, if researchers do not intervene, this means that the data collection is over, and that would be a missed opportunity to learn more about other aspects of an interface or other portions of data collection. An intervention is when a researcher helps the participant move forward by providing advice. Before beginning any data collection involving people with disabilities, a researcher should have a clear decision on if any interventions will be allowed, under what circumstances, how they will be documented, and how this will be accounted for in reporting the results.

16.4 LOGISTICS

16.4.1 COMMUNICATING WITH POTENTIAL PARTICIPANTS

When recruiting potential participants, it is important to understand their preferred method of communication and any related challenges. For instance, email may not be the preferred option for users with spinal cord injuries (SCI), as it may be harder

for users with SCI to generate text. Instead, phone calls might be the preferred option (Feng et al., 2005). Obviously, phone calls would not work well for Deaf people, who may prefer email or text messaging, or sign language over video. You may need to engage with sign language interpreters to begin the conversation about potentially taking part in research. Other user populations may have different challenges in communication. For instance, email is often a preferred method of communication for Blind users. However, due to the large amount of time required for them to process spam email, Blind users tend to have very strong filtering on their email. Emails sent to multiple Blind users using the BCC option will not make it through the spam filter to most users (Lazar et al., 2005). So for Blind users, it is important to place the recipients' email address in the "To" line, not in the "CC" line or "BCC" line. Another approach for Blind users might be, if you have access to their phone numbers, to call them on the phone. For users with some types of cognitive impairment, it may be necessary to contact caregivers.

16.4.2 PILOT STUDIES

Due to the complex logistics involved in research involving participants with disabilities, it is a good idea, when possible, to do pilot studies before beginning any real data collection. Your simulations in the lab, or your expectations of how a user will interact, are likely to be very different from the reality. While this is true in any type of HCI research, it is especially true in working with users with disabilities. Since you may have access to a limited number of users and you won't have any opportunity to do the data collection a second time, you need to confirm or address your perceptions early on in the process by doing a pilot study with one or two users.

Pilot studies can uncover a number of problems. For instance, is the documentation accessible for the specific user population? Users with spinal cord injuries can't physically handle documentation, and Blind users may not be able to use printed materials or even Braille materials (approximately 10%–20% of Blind individuals are fluent in Braille). Users in wheelchairs will need physical settings, including computer desks, and buildings, that can accommodate their wheelchairs. Other technical problems may also arise. For instance, any text documents sent to users before a study, must work, for Blind users under multiple screen readers (Window-Eyes, JAWS, VoiceOver and NVDA), multiple operating systems (OS X, Win XP, Win 7/8/10), and multiple text editors (MS-Word, OpenOffice, etc.), as well as various combinations of screen reader, operating systems, and text editor (Lazar et al., 2005). Sometimes the file format that works best is Rich Text Format, which tends to work with most text editors. In doing a pilot study, you may find out that the participants expect to use aids (such as a portable notetaker, voice recorder, or electronic device) or expect you to have aids available to them (Sauer et al., 2010). Consider that different assistive technologies are not equal, for instance, some screen readers have OCR (optical character recognition) built into them to analyze graphic documents, whereas other screen readers do not. Generally, you need to be aware if all participants are using certain aids; if only some of them do, you need to find a way

to compensate for that in your data collection. Also there may be conceptual misunderstandings, for instance, the coauthors of this book had the experience of running a pilot study, where the two Blind users in the pilot study, did not have the awareness of the structure of menu design that was expected. The coauthors adjusted the methodology accordingly.

One or two participants in the pilot study are generally enough, just to confirm that you are on the right track and that there are no major problems with logistics. If you have worked with a specific user population for a long time, you may have a few users that you collaborate with regularly, who are comfortable with you, and are willing to help you test out materials, be brutally honest, and serve as your “reality check.” Whatever flaws or problems are discovered during the pilot study should be modified and accounted for, before the main study begins.

16.4.3 SCHEDULING DATA COLLECTION INVOLVING USERS WITH DISABILITIES

Transportation may be an issue for some users with disabilities. It is important to remember that users with some perceptual, cognitive, or motor disabilities may not drive a car, or may live in a location where having a car is not feasible. They may rely on rides from others, public transportation, taxis, Uber/Lyft, paratransit, and other scheduled services to get from point A to point B. Therefore, these users must typically be scheduled for data collection enough in advance to secure transportation. It is often not possible for these participants to make transportation plans, or change them, at the last minute.

Rather than asking participants to come to a university or remote location, it may be preferable for researchers to offer to go to a home or workplace location. To help ensure the safety and security of researchers entering participant homes, it is preferable to go in teams of at least two researchers. By visiting users in their home or workplace, it alleviates the need for the user with a disability to schedule transportation to a new location. In addition, getting a glimpse of the user in their own environment, using their own technical setup, is likely to lead to a more ecologically valid data collection effort. Note the previous section in this chapter, about using consistent technology, versus a user's own technical configuration. Visiting the user in his or her natural environment allows the user to be most relaxed and productive and yields the most ecologically valid data. However, it is possible to either have users bring their own technology to a research lab, or to bring a standardized technology configuration to a user's workplace or home. The physical environment and the technical environment are not necessarily linked.

The major drawback of visiting users in their work or home environment is that you tend to have less control over the environment (Feng et al., 2005). If users are able to come to a research lab, this offers the researchers more control over the layout and noise in the environment. However, apart from the transportation challenge, there is another major challenge: the accessibility of the researchers' building. Researchers must be completely certain that the building that they expect users to come to, is

fully accessible. This means that the doors must be wide enough, restrooms must have accessible stalls, elevators must be present, and Braille must be available on all signs. In addition, some users may have service animals working with them (Feng et al., 2005).

It is also important to note that some users with disabilities are not involved in paid employment. Because employment is an important point of pride, those who are employed may be very sensitive about missing work for an outside research project. They are unlikely to let a research study interfere with their job performance (Lazar et al., 2006). It may be necessary to schedule research sessions during evenings or weekends. If, as researchers, you visit users in their workplace, be sensitive about not requiring more time for the research study than you had indicated to users, so that it will disrupt their work. In such circumstances, perhaps, it might be preferable to visit users at their homes, rather than their workplaces.

It is important for researchers to understand that the variety of users and the various levels of severity of the disability (see previous sections in this chapter) mean that the time involved for a user to take part in a research study might be relatively unpredictable. The researcher's schedule should be left flexible enough that it is not a problem if a participant takes much longer for data collection than is expected. In addition, many people with disabilities are determined to prove that they can accomplish tasks. This means that if the time period is limited for the specific participant's data collection, they may still want to continue and may feel the need to complete the task. For a researcher to tell the user that "time is up" may be met with resistance. This is generally not a problem, except that it needs to be accounted for in the scheduling of users.

16.4.4 INVOLVING PARTICIPANTS WITH COGNITIVE DISABILITIES/INTELLECTUAL IMPAIRMENTS

When involving people with various disabilities in research, the research methods are generally the same, but often the logistics are what change. There's a concreteness that people with cognitive disabilities often need for participating in research. For instance, Erazo and Zimmermann (2015), in evaluating a simplified banking interface for people with cognitive disabilities, noted that nearly all of their 11 participants wanted to have a printed confirmation of a banking transaction for their records. In their evaluation of multitouch screens by people with Down syndrome, Kumin et al. (2012) noted that it is important to use real accounts, and real data (rather than fake or test accounts), because for people with cognitive disabilities, they may not feel comfortable using "someone else's account."

There are other adjustments that may need to be made. For instance, in their research study which used eye-tracking devices to measure document reading in people with Autism, Yaneva et al. (2015) noted that participants with Autism sometimes asked for the lights to be diminished due to some sensory issues. Other researchers experienced how participants with Autism, when evaluating mobile phone apps for independent living, may be sensitive to noise and smells, such as those that commonly

occur in the kitchen (Tang et al., 2016). Typical workplace distractions, such as open workspaces with cubicles, colleagues talking, and software notifications (such as the sound when a new email message arrives) can also be distracting for people with Autism (Morris et al., 2015). For people with cognitive disabilities who are taking part in research, researchers should be aware of issues such as a dramatically different length of attention span between participants with the same disability, and some participants may need multiple breaks or frequent reminders to stay focused on the task, or more time to understand and answer the questions (surveys or interviews). Asking those familiar with the specific cognitive disability may help, for instance, in their study of email applications for people with Aphasia, Mahmud and Martens (2015) were told by speech pathologists, to design questionnaires such that there were no items on the far right of the page, where people with Aphasia might miss them.

It is important to ask people with cognitive disabilities, if they will be utilizing their own accounts, to bring the passwords written out on paper. Often, people with cognitive disabilities may have challenges related to memory or processing, and you must ask them to bring the passwords written out, because otherwise (1) they may forget the passwords, or (2) they may be saved on their computer at home (so that they typically will not need to login and remember the passwords) (Kumin et al., 2012; Ma et al., 2013).

For people with some cognitive disabilities (if they have visual strengths), it may be helpful to utilize a visual Likert scale (see Figure 16.1), which participants can simply point to. In their study of touchscreen usage by adults with Down syndrome, to help build on the visual strengths of people with Down syndrome, the following visual Likert scale was used (Kumin et al., 2012).



FIGURE 16.1

Visual Likert scale.

From Kumin, L., Lazar, J., Feng, J.H., Wentz, B., Ekedebe, N., 2012. A usability evaluation of workplace-related tasks on a multi-touch tablet computer by adults with Down syndrome. Journal of Usability Studies 7 (4), 118–142.

Sometimes, when doing research involving people with cognitive disabilities, you need to be flexible about the research methodology. Due to either the concreteness mentioned earlier, or challenges in social interaction or understanding, participants may sometimes ask researchers to do something different from the task that they were asked to do. Being flexible allows for the participant engagement to be high. For instance, participants may argue about data entry, because they were asked to write about winter clothing but it's currently summer, or they were asked to enter a party into a calendar application with a one hour length, but the participant says that a party must last at least 4 hours (Kumin et al., 2012). Researchers can be flexible, since the task is only slightly modified, to allow for participants to be more comfortable with the tasks.

It is sometimes hard to determine the level of cognitive impairment. So, cognitive or behavioral testing can be done, however, for many reasons, it's impractical for

HCI researchers to get results (for participants who have undergone cognitive testing, they may not want to share the results, and Institutional Review Boards (IRBs) may not approve the collection of cognitive testing data as a part of HCI research). Furthermore, for some cognitive disabilities, such as Autism, there may be people with Autistic traits who are not aware of their traits or who are not “out” as being people with Autism, primarily because of the discrimination that they worry they may face (Morris et al., 2015). The reader of this book should consult (Morris et al., 2015) for details on how to appropriately recruit people with Autism from within a specific company, where the individuals may not be publicly identified as having Autism.

One consideration that researchers often must make when doing research involving people with cognitive disabilities, is whether to focus on just one cognitive disability in their research, or to focus on the general category of “cognitive disability.” It is tempting to focus more broadly on cognitive disability, rather than on a specific cognitive disability, because recruiting participants with a specific cognitive disability can be a challenging experience. It's much easier to find 20 people to participate in research with “a cognitive disability” than to find 20 people with, say, “Traumatic Brain Injury” to participate. That's the reality. However, because someone has a cognitive disability doesn't mean that they are necessarily similar to other people with cognitive disabilities. So, for some participants, they may have varying levels of difficulty with memory, understanding, communication, visual, hearing, or social interaction (Ma et al., 2013). People with different types of cognitive disabilities generally are not similar. So, when possible, it's preferable to do research studies focusing on a population with a specific cognitive disability, recognizing, of course, that there are varying levels of severity within that population of users. It also needs recognizing that many of these individuals with a cognitive disability may not use any type of assistive technology, despite the public perception that all people with disabilities use assistive technology!

16.4.5 DOCUMENTATION FOR USERS WITH DISABILITIES

Often, there are a number of documents that are required for participation in a research study. These include IRB forms (also known as human subjects forms—see Chapter 15 for more information), instructions, task lists, and questionnaires. In traditional paper format, these forms may pose a problem for users who have what are known as “print disabilities,” people that have trouble seeing print (e.g., blind or low vision), handling print (e.g., users with spinal cord injuries), or cognitively processing print (e.g., users with dyslexia). It's also important to note that in some cases, if children with disabilities are involved in the research, then the researchers themselves may be required to submit their own approval paperwork related to criminal record background checks.

Depending on the regulations of the country in which the research is taking place, research projects involving human participants may require that participants sign a form, in which they understand that they are taking part in a research

experiment or project (see [Chapter 15](#) for detailed information on what rights human participants have). Most human subjects forms require handwritten signatures, as per university or institutional requirement. This may be a problem for a number of user populations. Users with motor impairments, especially those that are unable to use their arms, may not be able to use a pencil or pen to sign a form or handle a form. An audio recording, or a video of the user, agreeing to take part in the study, hopefully will be acceptable to the institutional review board. For users with certain types of cognitive disabilities, it's questionable whether they would be able to sign a legal document. A caregiver, who has legal standing, might need to provide the signature. For children with a disability, often the parents need to give their approval for participation in the research project. Blind participants can sign paper forms, but it's questionable whether we should ask participants to sign a form that they cannot read. For participants that either cannot read or handle the form, it is standard practice to send an electronic version of the form beforehand, so that the participant can read and be comfortable with it. Note that the informed consent is especially important for participants with disabilities, as they are used to being tested so often, that it is especially important to make them aware, for instance, that in much of HCI research, they are helping to inform design or improve usability, but they themselves are not being tested. If Blind participants are being asked to sign a paper form, the text on the form should be reread to them, and they will need guidance on where to sign the form. Be sure to understand the specific policies relating to IRB forms from the organization that approved the research study (usually a university). For instance, many universities accept nothing but a signed, paper-based form. Some universities are beginning to accept electronic versions of informed consent (again, see [Chapter 15](#)). It is helpful to check if your institutional review board can accept some modified form of informed consent, which may be more appropriate for your participant population. If the institutional review board or similar research authority will not accept audio or video recording of a user giving consent, there are work-arounds that can be utilized.

If a sponsoring organization requires signed forms from Blind users, there are two popular ways of guiding Blind users to the appropriate place to sign on the form. One method is to provide a signature guide (a small piece of plastic with a window in the middle, to indicate where the signature should be—see [Figure 16.2](#)). The other method is to attach a Braille label right below the signature line. The Braille label could say something along the lines of “sign above” ([Lazar et al., 2005](#)). While this might not be meaningful for the majority of Blind individuals who are not able to read Braille, the tactile information provided by the top line of the label can provide useful information on where the signature should be placed. Careful attention to details such as these can help build trust and confidence with participants, as they may appreciate that you've made the effort to make things work smoothly for them.

While human subjects forms are often the trickiest to deal with, this is primarily because there is often a legal requirement for a signed paper form. There is typically additional documentation in the research study, but there generally is

INFORMED CONSENT FORM FOR THE RESEARCH EXPERIMENT

Purpose of the Project:

Dr. Jonathan Lazar and his students are creating a research study to learn more about how blind users using screen readers become frustrated while surfing the web. With a better understanding of what frustrates users, we can come up with ways to improve the user experience. We hope that the results of this study will have beneficial effects to make computers less frustrating.

Procedures for Participants:

You will be asked to fill out a presession survey. After filling out the survey, you will be asked to perform your normal computer tasks for a minimum of two hours. Whenever you feel frustrated, you are asked to fill out a form, documenting your frustrating experience. After performing your normal tasks for a minimum of two hours, you are asked to fill out a postsession survey. You should then email all documents back to Dr. Lazar at Towson University.

Confidentiality:

Participation in this study is voluntary. All information will remain strictly confidential. Although the descriptions and findings may be published, at no time will your name or any other identification be used. You are at liberty to withdraw your consent to the experiment and discontinue participation at any time without prejudice. If you have any questions after today, please contact Dr. Jonathan Lazar at 410-704-2255 or contact Dr. Mark Broderick, Chairperson of the Institutional Review Board for the Protection of Human Participants at Towson University at (410) 704-6000.

I have read and understood the information on this form and had all of my questions answered.



The form consists of a large, dark gray rectangular box on the left, which contains a white rectangular area for the subject's signature. To the right of this box is a horizontal line for the date. The text 'Subject's Signature' is printed below the white area, and 'Date' is printed below the line.

FIGURE 16.2

An IRB form with a tactile signature guide for Blind users.

much more flexibility with the format of the other documentation. For instance, participants in research studies must often either read material, or record their responses, on paper. If users are unable to read printed documents or have trouble handling physical documents, then there are other options for use during the actual data collection. One option is to provide all of the materials in electronic format, which can be used both for reading and for recording responses. Plain text

versions of all documentation can be made available to the participants at the time of the research study. Only the IRB form should be made available beforehand, as providing actual study documents beforehand could lead to learning effects. Electronic formats may introduce another potentially complicating factor into the research study. For instance, what happens if some participants are more experienced with text readers or word processors than other users? Will that difference, even though it is not being measured or controlled for, make a difference in the outcome of the research?

The other option is to verbally instruct the participant on what to do and ask them to respond verbally. While this is very appropriate, the major caveat here is to make sure that rules are created to guide the researchers on what they do and do not say. For instance, is there a limit on the number of times that the researcher can repeat instructions? Do the researchers refuse to answer questions outside the scope of the instructions? Can they spell out words? For instance, if the research study was investigating web searching habits, it would not be appropriate for the researchers to give hints or provide guidance to the participants. Therefore, there should be clear rules for the researchers on what they can and cannot say, so that there is consistency across all participants taking part in the research study. Obviously, you must tailor the instructions and documentation to the needs of the participants. For instance, if participants have a motor disability, such as a spinal cord injury, in which case handling documents and recording responses on paper might be problematic, then audio recording might be a good option. If participants are Deaf-blind, Braille may be the preferred option. As always, you must know your participant population very well.

16.4.6 BRINGING EXTRA COMPUTER PARTS

When visiting users with disabilities in their home or workplace, it's important to understand that their setup may not be what most researchers are used to, and if utilizing the user's own technology, the technical setup will be out of the researcher's control. For instance, Blind users may not have a working monitor, Deaf or Hard of hearing users may not have working speakers, and users with motor disabilities may not have a working mouse. Since many of these participants have purchased a "standard package" of CPU, monitor, and peripherals from a computer company, if pieces of hardware that are useless to them break, there is no real incentive for the participants to replace them. However, researchers often rely on these tools to understand the participant interaction. For instance, often researchers who are visual will need to see the screen to understand what the screen reader is reading. If this is the case, you need to carry extra computer parts with you when you visit the users. For instance, bring a monitor with you if you are visiting Blind users in their workplace or home. Also bring standard cables (such as video and USB cables). If doing multiple on-site visits, it is good practice to take extra parts (monitors, cables, speakers, mice, external keyboards) with you at all times, as you never know when you may need them.

WHEN USERS GET FRUSTRATED

What happens if a user with a disability is taking part in a study, is not successful at completing any of the tasks, and is getting frustrated? This person is getting agitated, is still trying to complete the tasks, but clearly is not making any progress. What happens next? This is a realistic question. For the researcher who is observing this participant, it is an upsetting time. Although our research studies in HCI typically do not endanger health or leave lasting emotional effects, it is certainly possible that a situation of this nature could occur which could leave the user angry and upset. Apart from a few rare studies designed to frustrate people on purpose, such as (Riseberg et al., 1998), HCI research is generally not designed to aggravate the users who take part.

There are a few options. The researcher can remind the participant that they have the right to end their participation in the experiment, at any time, with no adverse consequences (which is typically a standard requirement in IRB forms). As part of this reminder, the researcher should note that whatever payment is due for participation will be given to the individual, regardless of when they end their participation. But if the participant does not want to end the session, what happens next? Perhaps the participant can be offered a short break or a period of rest, which would allow him or her a few minutes to calm down. The researcher technically has the right to end the experiment if they feel that someone is beginning to be harmed. However, for the researcher to unilaterally end the participation of the participant also sets some bad precedents. If researchers frequently end user participation, there could be some bias injected into the research study. This is a tricky situation. Especially when working with users with disabilities, who are often hard to recruit and replace.

16.4.7 PAYMENT

When paying participants for taking part in research, it is important to make sure that the form of payment will be useful to the participants. For instance, gift cards for a specific store (such as a local bookstore) may not be useful for some participants if they cannot use standard print materials. Also, gift cards that only work at a certain store may not be useful, if transportation is required to visit the store and use the gift cards. Gifts that are typically used to recruit university students for research, such as iPods, may also not be appropriate, as many users with disabilities have very specific technical needs and may not want to use new devices. The best forms of payment are either cash or cash equivalents, such as cash cards. If those are not viable options, then at least a gift card should be given at a store that has online ordering options and an accessible website (such as Amazon) or that has many local branches and many types of merchandise. It is also important to note that users with disabilities are typically paid more than users without disabilities for their participation in HCI research. One mistake of novice researchers is that they often assume that people

with disabilities do not need to be paid for their participation, but instead are “waiting around” to participate in research. This is not the case, and assuming such a scenario will not lead to either good long-term relationships, or people actually signing up to participate in your research.

16.5 SUMMARY

Research involving participants with disabilities can be challenging but it offers many rewards. The computer usage of many of these populations has not been explored in as much depth as with the general population of users, so there are many important research questions that remain unexamined, and people with disabilities should be involved in all types of HCI research. Before even recruiting people for a research study, it is important to learn more about the specific population of people with disabilities that you are interested in, and determine what their preferred terminology is, in terms of how their disability is referred to. Then, there are three areas which researchers need to pay careful attention to: (1) participants, (2) research methodology, and (3) logistics.

It's important to determine the specific inclusion criteria, what specific qualities (such as technology usage, education, occupation, employment, and severity of disability) would qualify someone to participate in the study. When recruiting participants with disabilities, it's a good idea to form long-term partnerships with disability advocacy organizations, and to think carefully about the best way to reach out to potential participants (in terms of technological communication and speech communication). Most research involving people with disabilities has a smaller number of participants, unless distributed approaches are used. It's also important to determine, for the participants in your study, if you want to use a consistent technical environment or instead use a “best case scenario,” both of which can be appropriate, depending on the specific research design. Pilot studies are especially important for research involving people with disabilities because there are so many logistical factors that must be considered and planned for in advance. It is especially important to consider transportation, and the accessibility of a research location, to ensure that participants can actually participate! There may also be modifications to a data collection method that need to be made when involving participants with cognitive or intellectual impairments. Documentation will often need to be presented in different formats, and it is important to ensure that participant payment is also in a format that is usable. With appropriate planning and attention to the participants themselves, the research methodologies, and the logistics, HCI research involving users with disabilities can be very successful.

RESEARCH DESIGN EXERCISE

Imagine that you are going to start doing research focused on people with a disability that has not yet received attention in the HCI research literature, for example, people

with Fragile X Syndrome. What are the first steps that you would take? Are there important considerations related to gender and communication? What groups could you reach out and connect with? What might the considerations be for recruiting participants? As a population of users without any preexisting research on computer usage, what research methods might be most appropriate? What modifications might you need to make to your methodology and logistics?

DISCUSSION QUESTIONS

1. What are five commonly used categories of inclusion criteria for determining whether someone with a disability can be included in a research study?
2. How do experience, confidence, technical environment, and previous barriers, influence perceptions of usability by participants with disabilities in research studies?
3. For what types of participants will you need to bring in sign language interpreters? How many sign language interpreters are typically needed?
4. Why are proxy users generally not considered valid for research? What are the limited circumstances where proxy users may be considered acceptable?
5. Why are small sample sizes considered acceptable in research involving people with disabilities?
6. What are the strengths and weaknesses of doing distributed research involving people with disabilities?
7. What are the strengths and weaknesses of doing case study research involving people with disabilities?
8. The chapter discusses the choice of using a consistent technical environment or using each user's individual technology environment. In what research scenario, and using what types of methods, would you want to utilize a consistent technical environment? In what research scenario, and using what types of methods, would you want to utilize each user's own technical environment?
9. What is a research intervention, and why might one be necessary when doing research involving people with disabilities?
10. What are three benefits of doing pilot studies involving participants with disabilities?
11. What are four methodological or logistical adjustments that you might need to make, when doing research involving people with cognitive disabilities?
12. What might three modifications be, to allow for people with disabilities to officially provide informed consent for participation in the research study?

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