

I. Historical and Current Issues Regarding Research Population

A. Contested Definitions

The terms used to describe the population of people with disabilities, and who is included in it, have shifted over many centuries. Older terms for people with physical, mental, and emotional disabilities dating from the 1600s to 1800s included “lame,” “furiously mad,” “lunaticks [sic],” “invalids,” “feeble-minded,” and many others. The last term endured into the 20th Century. More often in the 20th Century, however, the terms “crippled,” “handicapped,” or “disabled” were used.¹ While the former term has fallen out of general use, the latter two terms are still commonly seen. However, “disabled” is the preferred term; “handicapped” is a term that many find offensive.² Handicap can still be used to describe a barrier that impedes someone with a disability from equal access. For example, a wheelchair user who cannot walk has a disability in the sense that they cannot use stairs. A building that has stairs without a ramp presents a handicap by restricting their ability to access the building.

More recently, a debate has centered on the order between “people” and “disabilities.” Many U.S. scholars prefer the term *people with disabilities* because it emphasizes the essential personhood first, with disability status being an addition to that status. Conversely, scholars in Britain, Canada, and Australia have tended to use the term *disabled people* to draw attention to the minority status and group identity.³ As this toolkit is primarily focused on research in the U.S., we will tend to use people with disabilities (as the title demonstrates). However we will use the term “disabled people” when discussing a source that uses that term. Additionally, these are generalizations that may not apply in all circumstances. Some groups in the US, including Deaf people and Autistic people, prefer not to use people-first language, instead putting their identity first as a way of showing Disability Pride.⁴

There are many different ways to define who is disabled. In 2003, a federal government report identified 67 different legal and policy definitions of disability or handicap in U.S. statutes.⁵ While we will not attempt to provide all of them here, we will highlight a few important ones.

For the purpose of establishing eligibility for Social Security Disability Insurance and Supplemental Security Income, the Social Security Administration (SSA) considers someone disabled if they cannot undertake any gainful employment because of a medically determinable physical impairment that would result in their death or will be at least 12 months in continuous duration. Moreover, the disability must prevent them from obtaining and holding any employment, not just the job they were doing before they became disabled (if they had one). While this may sound reasonable, it actually involves a four-part evaluation for each of the more than three million applicants for assistance every year: a medical evaluation, an assessment of functional capacity, an analysis of their work history and skills, and a judgement about their prospects for employment. People with a variety of disabilities work in numerous different professions, making the calculus more difficult. This has proven to be costly: nearly one third of the SSA’s budget is dedicated to the determination process.⁶

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People with Disabilities

The landmark piece of legislation specifically focused on people with disabilities is the Americans with Disabilities Act (ADA). Passed in 1990, this set out three criteria for establishing disability:

- a) A physical or mental impairment that substantially limits one or more of the major life activities of the individual;
- b) A record of such an impairment; or
- c) Being regarded as having such impairment.⁷

Thus, the ADA recognizes multiple ways someone can be considered disabled: assessment that they have impairments that limit their functioning, or being perceived as having such an impairment. However, in practice, courts have given precedence to the first part while discounting the final part, and have narrowly interpreted the ADA, resulting in a much smaller population of people with disabilities than the Act's writers intended.⁸ This creates a problem when someone is discriminated against because they are perceived to have a disability, but the person is too capable to legally be considered disabled, leaving them no redress under the law. An example is the case of *Sutton v United Air Lines*: two pilots were not hired because they did not pass an eye exam without their glasses, but the Supreme Court ruled they could not use the ADA's protections against discrimination because their disability was correctable with glasses.⁹ The ADA Restoration Act has led to a somewhat less narrow interpretation, but it still is not at the level the bill's writers intended.

The US Census Bureau has an important role to play in providing estimates of the size of the population, including those with disabilities. It defines several different types of disability, including ambulatory, cognitive, employment, hearing, independent living, mental, physical, sensory, and self-care disabilities. The main data for disability come from the American Communities Survey. Starting in 2008, anyone who reports one or more hearing, vision, cognitive, ambulatory, self-care, or independent living difficulties is considered to have a disability. These tend to be two-part: both an impairment, and the way that impairment affects their ability to live their lives. For example, in order to be considered to have a cognitive difficulty, one must not only have, "a physical, mental, or emotional problem;" that problem must also cause them to have, "difficulty remembering, concentrating, or making decisions."¹⁰ One problem is that Census instrument does not reflect the most current usage: in the field of rehabilitation medicine, intellectual disability has replaced the term cognitive disability or impairment. It is unclear if and when the Census will change the wording of the questionnaire.

Thus, from three government entities, three very different definitions of disability exist. As the next section shows, these definitions are often expressions of the model people use to think about disability. We are not advocating for one particular definition of disability. Instead, we wish to highlight the varied ways that disability can be defined. What is necessary for your research is, as in most situations, to define the population being studied clearly.

Finally, the World Health Organization (WHO) has developed the International Classification of Functioning, Disability and Health (ICF) to standardize the definition of disability across the world and across different sectors, including in data collection and analysis. The ICF consists of four areas: impairments of body functions, impairments of body structures, activity limitations and participation restrictions, and environmental factors that act as barriers or facilitators. The ICF views disability as a continuum rather than a dichotomous classification. The ICF is operationalized through the WHO Disability Assessment Schedule. Further information can be found at <http://www.who.int/classifications/icf/en/>. Although the US is a member of the

WHO, and many professionals in the U.S. use this definition, it has not replaced the definitions used in the Social Security Administration, the Americans with Disabilities Act, or the Census Bureau. Thus, U.S. investigators should carefully consider which definition(s) will be most appropriate for their research.

B. Theories of Disability

Different objectives and theoretical frameworks underlie many of the conflicting definitions of disability. While other models exist, we will review four primary theories of disability here: the medical model, the functional model, the social model, and integrated models.

The medical model was one of the dominant frameworks for many centuries. This model views disability mainly as a phenomenon residing within the individual that is a result of injury, disease, or condition. People with disabilities are considered to be deviations from “normal” people; therefore medical professionals should do all they can to treat their conditions, so as to decrease disability. The medical model can provide clear distinctions that are useful for determining eligibility for government benefits. The disadvantages are that it views disability as “abnormal” and something to be cured, and it ignores the barriers society erects that frustrate the efforts of people with disabilities to live their lives.¹¹

By contrast, the functional model of disability focuses less on the causes of disability and more on the effects a disability has on a person’s ability to accomplish certain tasks and goals. Consequently, the focus of medicine is on interventions to improve functioning for individuals, through the use of therapies and devices (like wheelchairs or prosthetics). This model is clearly seen in the Social Security Administration’s evaluation of people’s ability to work. Like the medical model, the functional model of disability is simplistic and ignores the social and political aspects of disability, along with the barriers to access that society puts in front of people with disabilities.¹²

In contrast to the medical and functional theories of disability, in the social model of disability, society’s barriers take center stage. These can include social barriers like discrimination and stereotyping, physical barriers like stairs without ramps and signs without braille, economic barriers precluding participation in the general economy, and political factors like not addressing the needs of people with disabilities through public policy remedies. The Americans with Disabilities Act uses this model to construct its definition. While this model brings needed attention to the multiple dimensions of disability, some critics argue that it places too much emphasis on the social aspects while ignoring the very real physical, mental, and emotional impairments people may experience. It is also more complicated and therefore harder to understand than the preceding models.¹³

Finally, integrated models of disability attempt to combine existing models, amplifying strengths while addressing weaknesses. The World Health Organization has created the International Classification of Functioning, Disability, and Health (ICF), a biopsychosocial model of disability as well as a definition. The ICF acknowledges the role of health conditions while also incorporating environmental (such as social attitudes and the built environment) and personal factors (such as age and gender). Integrated models like the ICF attempt to synthesize previous models into a single, useful framework. However, integrated models of disability require an understanding of all the component parts along with their interplay, which can make these models difficult to apply and communicate outside the research world.¹⁴

C. History of Mistreatment by Health Professionals, Researchers, and Government Agencies

People with disabilities have faced mistreatment from health professionals, researchers, and government agencies for many years. Records indicate that over 47,000 sterilizations of people, many with mental disabilities, occurred in the U.S. between 1907 and 1949. Many physicians believed the treatment was beneficial, despite substantial evidence to the contrary; moreover, some justified sterilization based on eugenics, believing the preventing the birth of “defective” children was defensible and correct. Nazi Germany used a California program as the basis for its sterilization program for people with disabilities. New techniques were developed or more widely adopted during this period, including shock therapy and psychosurgery (such as a lobotomy). Again, these treatments had little therapeutic value and did more to harm and subdue people with disabilities than treat them.¹⁵

In Nazi Germany, medical and research professionals committed many horrific acts against people with disabilities. *Aktion T4* was the involuntary euthanasia program of people with disabilities that killed nearly 300,000 people; this program is often regarded as providing the blueprint for the larger campaign to murder European Jews and other populations the Nazis attempted to exterminate.¹⁶ Among the many atrocities Nazi researchers committed, some of the most infamous are those of Josef Mengele. People with disabilities featured prominently in his perverse experiments. In one, a twin with an arched back was sewn to the twin with a straight back; this was done poorly and caused gangrene. When Mengele found a father with an arched back whose son had an abnormal foot, he had them murdered, their bodies boiled so the bones could be more easily extracted, and then proceeded to examine their skeletons. He also paraded seven Little People naked in front of a visiting bureaucrat, explaining their Jewish lineage, in the hopes of receiving a promotion. Contemporary witnesses describe his attitude towards inmates at Auschwitz as those a researcher might have towards lab rats, with complete disregard for their thoughts, feelings, and suffering.¹⁷ These incidents are small glimpses into the systematic cruelty he and other researchers inflicted on people with disabilities.

Further research abuses happened in the U.S. in the post-World War Two period; one example is the Willowbrook Hepatitis Experiments. Starting in 1955 and continuing into the 1970s, Saul Krugman and his colleagues from the New York University School of Medicine conducted a series of experiments on mentally disabled children at the Willowbrook State School in New York. In some of the experiments, children who had been given hepatitis antibody injections were deliberately injected with a live form of the virus, to see how they reacted. Though parental consent was obtained, it was not free from coercion, because participating in the study could allow their children to be admitted to the school, which was seen as a desirable destination for the children. Moreover, the study could have been conducted with adults, who could consent for themselves, rather than children. There were some benefits from the study in terms of knowledge about the disease and its treatment, as well as a reduction in the overall number of cases of hepatitis in the clinic. However, that does not justify the many flawed aspects of the study.¹⁸

It might be comforting to think of these examples as history that is long past. However, mistreatment is not confined to many decades or centuries ago but still happens today. Involuntary sterilizations continue to occur. A comprehensive literature review of studies in the United States noted that people with disabilities were more likely to be abused by health care providers, partially because of increased contact, and partially because more time in healthcare settings puts them in more vulnerable spaces. Additionally, people who have a personal

assistance worker face the prospect of abuse from that care provider.¹⁹ Beyond the U.S., a review article in the *Lancet* found that people with mental and psychosocial disorders worldwide face substandard living conditions in residential facilities; physical, mental, and sexual abuse; neglect; and harmful practices incorrectly labeled as treatments, including the continued use of electroconvulsive therapy.²⁰

Thus, the abuses of the past continue into the present, making many people with disabilities skeptical of participating in research. Time and care are needed to forge trust with possible research participants, addressing their concerns and questions.

D. Health Disparities

Healthy People 2020 identified risk factors people with disabilities face that lead to adverse health outcomes. Compared to people without disabilities, people with disabilities are less likely to receive preventive health services and engage in necessary physical activity; however, they are more likely to smoke cigarettes. Factors such as these, plus complications related to their conditions, mean people with disabilities are at increased risk for obesity, hypertension, and depression.²¹ Closing the gap on these disparities will be difficult without sufficient evidence tailored to the needs of people with disabilities. Therefore, there is a great need to enroll people with disabilities in more research studies.

E. Underrepresentation in Research Not Specifically Related to Disability

An ongoing problem in disability studies, particularly in the realm of disability health, is the lack of good quality data about people with disabilities. People with disabilities are underrepresented in general health research (that is, health research not specifically focused on disability or a disabling condition). Some possible reasons include lack of adaptation of study procedures to accommodate people with disabilities, as well as using disability as an exclusionary criterion even when not related to scientific objectives. Consequently, it is unknown if health guidelines and treatments are applicable to this population. For example, how does physical activity impact risk for cardiac disease among people with mobility impairments? How does blood monitoring impact diabetes control for blind people?²² Consequently, Healthy People 2020 called for increased research on the health of people with disabilities; two of the three emerging issues it identified relate to this goal. Firstly, it identified a need for better population data, to be gathered by including disability in all public health surveillance tools. Secondly, it called for greater implementation of evidence-based interventions, which will require translating successful clinical programs to community settings.²³ See Section V for recommendations on including people with disabilities in research not specifically focused on disability.

F. Multiple Sources of Identity

An individual's disability status should be viewed in the context of multiple identities. In addition to disability, their race and ethnicity, sexual orientation, gender identity, citizenship status, class, and many other aspects influence how they view themselves and their risk and resilience factors for health outcomes. Recognizing these dynamics is a critical step to building relationships with research participants.

F. Engaging the Community in Research

Historically, people with disabilities were treated as a deviation from “normal” in much of the research on disability. Paralleling the development of models of disability, disability research has more recently challenged the idea of non-disability being normal. Part of the impetus for this change was the increased involvement of people with disabilities themselves in research. Increasing the involvement of the community being studied is a key component of community-engaged research (CENR), community-based participatory research (CBPR), and participatory action research (PAR). The population being studied participates in as many aspects of the research as possible, with the requirements for the former being less exhaustive than the latter two approaches. However, all share a desire to produce research that can make a positive impact on the lives of the people in the population as well.²⁴ See Section V, Recruitment and Retention Best Practices, for further information.

¹ Bickenbach, J.E. (2012). Introduction, Background, and History. In G.L. Albrecht (Ed.), *Disability Key Issues and Future Directions: Ethics, Law, and Policy*. Thousand Oaks, CA: Sage Publications.

² Definition of Handicap. (2018). *Miriam-Webster*. Retrieved from <https://www.merriam-webster.com/dictionary/handicap>.

³ Albrecht, G.L. (2012). Series Introduction. In G.L. Albrecht (Ed.), *Disability Key Issues and Future Directions: Ethics, Law, and Policy*. Thousand Oaks, CA: Sage Publications.

⁴ Syracuse University Disability Cultural Center (DCC). (2014). An Introductory Guide to Disability Language and Empowerment. *Syracuse University*. Retrieved from <http://sudcc.syr.edu/LanguageGuide/>.

⁵ Bickenbach, J.E. (2012). Introduction, Background, and History. In G.L. Albrecht (Ed.), *Disability Key Issues and Future Directions: Ethics, Law, and Policy*. Thousand Oaks, CA: Sage Publications.

⁶ Bickenbach, J.E. (2012). Current Issues, Controversies, and Solutions. In G.L. Albrecht (Ed.), *Disability Key Issues and Future Directions: Ethics, Law, and Policy*. Thousand Oaks, CA: Sage Publications.

⁷ Americans with Disabilities Act of 1990, 42 USC 126 (Section 12102). Retrieved from <https://www.ada.gov/pubs/adastatute08.htm#12102>.

⁸ Bickenbach, J.E. (2012). Current Issues, Controversies, and Solutions. In G.L. Albrecht (Ed.), *Disability Key Issues and Future Directions: Ethics, Law, and Policy*. Thousand Oaks, CA: Sage Publications.

⁹ Bickenbach, J.E. (2012). Introduction, Background, and History. In G.L. Albrecht (Ed.), *Disability Key Issues and Future Directions: Ethics, Law, and Policy*. Thousand Oaks, CA: Sage Publications.

¹⁰ How Disability Data are Collected from The American Community Survey. (2017). *US Census Bureau*. Retrieved from <https://www.census.gov/topics/health/disability/guidance/data-collection-acs.html>.

¹¹ Mullner, R.M. (2011). Introduction, Background, and History. In G.L. Albrecht (Ed.), *Disability Key Issues and Future Directions: Health and Medicine*. Thousand Oaks, CA: Sage Publications.

¹² Mullner, R.M. (2011). Introduction, Background, and History. In G.L. Albrecht (Ed.), *Disability Key Issues and Future Directions: Health and Medicine*. Thousand Oaks, CA: Sage Publications.

¹³ Mullner, R.M. (2011). Introduction, Background, and History. In G.L. Albrecht (Ed.), *Disability Key Issues and Future Directions: Health and Medicine*. Thousand Oaks, CA: Sage Publications.

¹⁴ Mullner, R.M. (2011). Introduction, Background, and History. In G.L. Albrecht (Ed.), *Disability Key Issues and Future Directions: Health and Medicine*. Thousand Oaks, CA: Sage Publications.

¹⁵ Braddock, D.L., & Parish, S.L. (2001). An Institutional History of Disability. In G.L. Albrecht, K.D. Seelman, and M. Bury (Eds.), *The Handbook of Disability Studies*. Thousand Oaks, CA: Sage Publications.

¹⁶ Bryant, M.S. (2005). *Nazi Euthanasia on Trial, 1945-1953*. Boulder, CO: The University Press of Colorado. Retrieved from <http://www.jstor.org/stable/j.ctt1wn0r98>.

¹⁷ Posner, G.L. & Ware, J. (1986). *Mengelle: The Complete Story*. New York, NY: McGraw Hill.

¹⁸ National Institutes of Health. (2009). *Exploring Bioethics*. Newton, MA: Educational Development Center, Inc. Retrieved from <https://science.education.nih.gov/supplements/ExploringBioethics.pdf>.

¹⁹ Plummer, S.-B., & Findley, P.A. (2012). Women with Disabilities' Experience with Physical and Sexual Abuse: A Review of the Literature and Implications for the Field. *Trauma, Violence, & Abuse*, 13(1), 15-29. DOI: 10.1177/1524838011426014.

²⁰ Drew, N., Funk, M., Tang, S., Lamichhane, J., Chavez, E., Katontoka, S., Pathare, S., Lewis, O., Gostin, L., & Saraceno, B. (2011). Human Rights Violations of People with Mental and Psychosocial Disabilities: An Unresolved Global Crisis. *The Lancet*, 378, 1664-1675. DOI: 10.1016/S0140-6736(11)61458-X.

²¹ Disability and Health. (2018). Healthy People 2020. *Office of Disease Prevention and Health Promotion, Department of Health and Human Services*. Retrieved from <https://www.healthypeople.gov/2020/topics-objectives/topic/disability-and-health?topicid=9>.

²² Williams, A.S., & Moore, S.M. (2011). Universal Design of Research: Inclusion of Persons with Disabilities in Mainstream Biomedical Studies. *Science Translational Medicine*, 3(82), 82cm12. <http://doi.org/10.1126/scitranslmed.3002133>.

²³ Disability and Health. (2018). Healthy People 2020. *Office of Disease Prevention and Health Promotion, Department of Health and Human Services*. Retrieved from <https://www.healthypeople.gov/2020/topics-objectives/topic/disability-and-health?topicid=9>.

²⁴ Brown, S.C. (2001). Methodological Paradigms that Shape Disability Research. In G.L. Albrecht, K.D. Seelman, and M. Bury (Eds.), *The Handbook of Disability Studies*. Thousand Oaks, CA: Sage Publications.

II. Health and Research Practice

A. Best Practices and Interventions

Cancer Screening: Reducing Structural Barriers for Clients – Breast Cancer

<https://www.thecommunityguide.org/findings/cancer-screening-reducing-structural-barriers-clients-breast-cancer>

Cancer Screening: Reducing Structural Barriers for Clients – Colorectal Cancer

<https://www.thecommunityguide.org/findings/cancer-screening-reducing-structural-barriers-clients-colorectal-cancer>

Epilepsy Across the Spectrum: Promoting Health and Understanding

<http://www.nationalacademies.org/HMD/Reports/2012/Epilepsy-Across-the-Spectrum.aspx>

The Future of Disability in America – Institute of Medicine Report

<https://www.nap.edu/catalog/11898/the-future-of-disability-in-america>

Interventions for Improving Employment Outcomes for Workers with HIV

<http://cochranelibrary-wiley.com/doi/10.1002/14651858.CD010090.pub2/full>

Interventions to Improve Return to Work in Depressed People

<http://cochranelibrary-wiley.com/doi/10.1002/14651858.CD006237.pub3/full>

Organizing Healthcare Services for Persons with an Intellectual Disability

<http://cochranelibrary-wiley.com/doi/10.1002/14651858.CD007492.pub2/full>

Vaccination Programs: Home Visits to Increase Vaccination Rates

<https://www.thecommunityguide.org/findings/vaccination-programs-home-visits-increase-vaccination-rates>

Worksite: Seasonal Influenza Vaccinations Using Interventions with On-Site, Free, Actively Promoted Vaccinations – Healthcare Workers

<https://www.thecommunityguide.org/findings/worksite-seasonal-influenza-vaccinations-healthcare-on-site>

B. Searchable Database:

Healthy People 2020 Best Practice Research Search

<https://www.healthypeople.gov/2020/tools-resources/Evidence-Based-Resources>

III. National and Local Data

A. General Data

Pew Research Center

7 Facts about Americans with Disabilities

<http://www.pewresearch.org/fact-tank/2017/07/27/7-facts-about-americans-with-disabilities/>

Disability in the Digital Age

<http://www.pewinternet.org/2012/08/06/disability-in-the-digital-age/>

Disabled Americans are Less Likely to Use Technology

<http://www.pewresearch.org/fact-tank/2017/04/07/disabled-americans-are-less-likely-to-use-technology/>

A Political Profile of Disabled Americans

<http://www.pewresearch.org/fact-tank/2016/09/22/a-political-profile-of-disabled-americans/>

US Census Bureau

Aging-Accessible Homes (Visualization)

<https://www.census.gov/library/visualizations/2017/comm/again-accessible-homes.html>

Americans With Disabilities: 2010

<https://www.census.gov/library/publications/2012/demo/p70-131.html>

Disability among the Working Age Population: 2008 and 2009

<https://www.census.gov/library/publications/2010/acs/acsbr09-12.html>

Disability Characteristics of Income-Based Government Assistance Recipients in the United States: 2011

<https://www.census.gov/library/publications/2013/acs/acsbr11-12.html>

The Disability of Veterans

<https://www.census.gov/library/working-papers/2016/demo/Holder-2016-01.html>

Educational Attainment in the United States: 2015

<https://www.census.gov/library/publications/2016/demo/p20-578.html>

Employment Status and Occupations of Gulf War-Era Veterans

<https://www.census.gov/library/publications/2014/acs/acsbr13-22.html>

How Common Are Specific Disabilities by Age? (Visualization)

<https://www.census.gov/library/visualizations/2017/comm/cb17-ff11-disabilities.html>

Older Americans with a Disability: 2008–2012

<https://www.census.gov/library/publications/2014/acs/acs-29.html>

Our Nation's Veterans - Distribution of Civilian Veterans, 18 Years and Over in the United States and Puerto Rico

<https://www.census.gov/library/visualizations/2015/comm/our-nation-s-veterans.html>

Prevalence of Disabilities for Ages 18+ (Visualization)

https://www.census.gov/library/visualizations/2016/comm/cb16-ff12_disabilities.html

The Relationship Between Health Conditions and the Core Disability Question Set

<https://www.census.gov/library/working-papers/2017/demo/SEHSD-WP2017-12.html>

The Research Supplemental Poverty Measure: 2012

<https://www.census.gov/library/publications/2013/demo/p60-247.html>

School-Aged Children With Disabilities in U.S. Metropolitan Statistical Areas: 2010

<https://www.census.gov/library/publications/2011/acs/acsbr10-12.html>

Understanding Changes in the Disability Prevalence in the 2014 Survey of Income and Program Participation: Three Explanations Considered

<https://www.census.gov/library/working-papers/2018/demo/SEHSD-WP2018-04.html>

CDC Wonder

<https://wonder.cdc.gov/>

Disability Statistics

<http://www.disabilitystatistics.org/>

National Council on Disability

Transportation Update: Where We've Gone and What We've Learned

https://ncd.gov/rawmedia_repository/862358ac_bfec_4afc_8cac_9a02122e231d.pdf

B. State and Local Data

Chicago Metropolitan Agency for Planning: ADA Transition Plans for Your Community(Includes data on prevalence of people with disabilities in the Chicago area)

<http://www.cmap.illinois.gov/documents/10180/142101/ADAPresentation121116.pdf/7aebba45-a162-43d4-980a-d4526e97d783>

City of Chicago: Facts and Figures about People with Disabilities in Chicago and the U.S.

https://www.cityofchicago.org/city/en/depts/mopd/supp_info/guidelines_for_writingandreportingaboutpeoplewithdisabilities/facts_and_figuresaboutpeoplewithdisabilitiesinchicagoandtheus.html

Cornell University: 2016 Disability Status – Illinois

http://www.disabilitystatistics.org/StatusReports/2016-PDF/2016-StatusReport_IL.pdf?CFID=9351924&CFTOKEN=13889418b8fdd7c7-C4985E40-A24A-79D6-ABDEAB08C67A8C3B

Greater Chicago Food Depository: Food Insecurity among Adults with Disabilities in Cook County – Realities and Remedies

<https://www.chicagosfoodbank.org/disabilities-food-insecurity/>

Voorhees Center for Neighborhood and Community Development at UIC: How Accessible is Chicago Transit to Persons with Disabilities?

<https://voorheescenter.wordpress.com/2015/11/20/how-accessible-is-chicago-transit-to-persons-with-disabilities/>

US Census Bureau

Chicago Quick Facts

<https://www.census.gov/quickfacts/fact/table/chicagocityillinois/HSD410215>

Illinois Community Facts

https://factfinder.census.gov/faces/nav/jsf/pages/community_facts.xhtml?src=bkmk

Illinois Quick Facts

<https://www.census.gov/quickfacts/IL>

IV. Ethical and Regulatory Issues

While many important ethical and regulatory issues concern people with disabilities, we will focus here on those related to research.

A. Applying the Belmont Report: Principle of Respect for Persons

One of the three key principles of the Belmont Report is respect for persons. This principle is made up of two components: “first, that individuals should be treated as autonomous agents, and second, that persons with diminished autonomy are entitled to protection.”²⁵ Tension can occur in defining whether and to what extent people have diminished autonomy. The report specifically mentions illness and mental disability as possible reasons for reduced self-determination. When someone has been determined to be in this situation, a family member, friend, or state entity typically makes the decision on whether they will participate in research or not. There has been some push-back on this idea from disability scholars, who see a parallel with the past denial of autonomy for marginalized groups, such as African Americans. Instead, they propose supportive decision making, where individuals are provided whatever support they need to make their choice. Moreover, interviews with people with intellectual and developmental disabilities have shown a desire to be included in research.²⁶ This has been incorporated into the UN Convention on the Rights of Persons with Disabilities.²⁷ However, the U.S. has signed but not ratified this treaty, meaning it has essentially no power in this country.²⁸ Thus, the use of a surrogate is still the most common practice for people with reduced decision-making capacity. It is good practice to inform as fully as possible and seek the assent of someone with reduced autonomy in addition to the person making legal decisions for them.

Federal regulations state that people with intellectual and developmental disabilities are a vulnerable population that should have special protection, but they do not explain these definitions and their implications for research practice. At UIC, assent from potential participants who have diminished capacity to give consent, along with the consent of their legally authorized representatives, must be given for them to participate in research. Guidance specific to the UIC IRB can be found at <http://research.uic.edu/node/758>.

Tools are available to help determine a potential participant’s capacity to consent. One such tool, the MacArthur Competence Assessment Tool for Clinical Research (MacCAT-CR), is available at http://www.prpress.com/MacArthur-Competence-Assessment-Tool-for-Clinical-Research-MacCAT-CR_p_167.html (fee required).

B. Assumptions and Values Underlying Research and Measurement

One criticism disability scholars and activists have made of medicine is the assumption that full health and normal functioning are the key values of human life. One example is the disability-adjusted life year, which estimates the amount of life and functioning lost due to death and disability, had they been able to live a full, “healthy” life.²⁹ Even though this metric does not necessarily measure quality of life, that is how it is often used. Plus, it puts disability on the same plane as death, and many argue that is not appropriate or accurate. Disability scholars and advocates suggest that full health and normal functioning have value but are not the only valuable things in life, and that they should be seen in the context of other considerations. For example, many individuals with reduced functioning and therefore “objectively” leading lives of lower quality often rate their

quality of life quite highly. These considerations have many implications for research: is the goal of research to cure a disease or condition, to improve functioning, or to create conditions that allow for greater participation regardless of functioning?³⁰ Most likely, it is not any one of these, but some combination thereof, that should be the goals of research. Therefore, engagement of the population being studied is critical before developing treatments or interventions, lest your research aim to fix a problem that people with disabilities do not see as a problem, or see as less important or immediate than other problems.

²⁵ National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. (1978). *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research*. Bethesda, MD: The Commission. Retrieved from https://www.hhs.gov/ohrp/sites/default/files/the-belmont-report-508c_FINAL.pdf.

²⁶ McDonald, K.E., Kidney, C.A., & Patka, M. (2012 February 1). 'You Need to Let Your Voice be Heard:' Research Participants' Views on Research. *Journal of Intellectual Disability Research*, 57(3), 216-225. <https://doi.org/10.1111/j.1365-2788.2011.01527.x>.

²⁷ Bickenbach, J.E. (2012). Current Issues, Controversies, and Solutions. In G.L. Albrecht (Ed.), *Disability Key Issues and Future Directions: Ethics, Law, and Policy*. Thousand Oaks, CA: Sage Publications.

²⁸ Helderman, R.S. (2012 December 04). Senate Rejects Treaty to Protect Disabled Around the World. *Washington Post*. Retrieved from https://web.archive.org/web/20130921055440/https://articles.washingtonpost.com/2012-12-04/politics/35624605_1_treaty-disabled-children-americans-with-disabilities-act.

²⁹ Metrics: Disability-Adjusted Life Year (DALY). (2018). *World Health Organization*. Retrieved from http://www.who.int/healthinfo/global_burden_disease/metrics_daly/en/.

³⁰ Bickenbach, J.E. (2012). Current Issues, Controversies, and Solutions. In G.L. Albrecht (Ed.), *Disability Key Issues and Future Directions: Ethics, Law, and Policy*. Thousand Oaks, CA: Sage Publications.

V. Recruitment and Retention Best Practices

A. Universal Design for Research

A promising model for increasing participation of people with disabilities in general research is Universal Design for Research, or UDR. Taking inspiration from Universal Design in architecture, where structures and environments are designed so that all people can use them without further adaptation, UDR provides four rules for making research more inclusive:

1. Plan your research to include all potential participants who meet the inclusion criteria, regardless of their current abilities or disabilities;
2. Do not create exclusion criteria unless there is a compelling scientific rationale;
3. Provide multisensory, flexible options for recruitment, research instruments (such as questionnaires), measurements, and responses from participants, with reasonable accommodations that invite and facilitate participation by persons with disabilities; and
4. When you do not know how to include someone with a disability, consult someone who does (the potential research participant, another person with that disability who is knowledgeable about the range of methods people use for living fully with it, or a professional who works with persons who have that disability).³¹

Following these principles can allow people with disabilities to participate in many types of research without significant modifications or added costs. This would be in keeping with the Belmont Report principle of justice, that populations should not be unduly excluded from participating in research.

B. Community-Based Participatory Research with People with Disabilities: Principles

One of the rallying points of the disability rights movement has been, “Nothing about us without us.”³² This phrase represents a reaction against the way that disability care, policy, and research had been led through much of the 20th Century by people who did not have disabilities. As such, listening to and respecting the opinions and wishes of research participants with disabilities is critically important, especially if you or other people on your research team are not disabled.

As mentioned in Section I, Community-Based Participatory Research (CBPR) and Participatory Action Research (PAR) are complimentary methods for addressing the hesitance some people with disabilities have for participating in research. A major tenet of CBPR is that community members (either on their own or through organizations) have a real voice in setting the research agenda, planning the project, implementing the plan, and realizing outcomes. Relatedly, the community should see real benefits from the process in addition to the generation of knowledge that benefits the researcher.³³ Similarly, PAR typically results in action steps that achieve or move towards a material improvement in the lives of the people who participated in the research. Four principles inform the approach: power sharing, mutual respect for experience and expertise, informed decision making, and maximum involvement [of participants in the research process].³⁴ These are approaches to research more than specific methodologies; though they naturally fit with qualitative research, they can also be used in quantitative and mixed-methods research as well.

C. Engaging People with Disabilities in Research: Moving from Principles to Action

A challenge to enacting these principles is that, in order to obtain funding to do research, much of the agenda setting and planning must be done prior to submitting most proposals. One approach is to do the initial relationship building and planning before applying for a grant. You can also begin discussions with community-based organizations and volunteer to fill a need or help with existing projects before embarking on a research project. Similarly, if you have funding for a small, short-term study, this can be a way to build the groundwork for a more substantial partnership.³⁵ These approaches may require more hours for both the researchers and the community partners. Ultimately, though, they can result in a stronger partnership because of the shared commitment that everyone builds together.

After the initial period of relationship building, a few key considerations can help the partnership transition into a robust engagement. Creating a community advisory board (CAB) is essential to the process. Potential members should be committed to the project and be willing to work with their contacts in the community to build further support for the project. Members should come from multiple organizations or places in the community to ensure continuity if one organization reduces its support of the project. Convening a CAB helps bring accountability to the project, but it also is a signal to others in the community that buy-in from their community is already present. Beyond convening the CAB, it is important for the researcher to attend events outside the project, and to be physically present for meetings, to demonstrate their commitment.³⁶ At least some project-related meetings should be held in community settings, not on a university campus. Having meetings on community partners' home turf allows more people to participate because they have a shorter distance to travel and/or are familiar with the spaces. Additionally, a setting like a school or community center can allow participants to show products from past projects of which they are proud or illustrate things that need improvement. Community involvement should continue after data collection. Community partners should be involved in member-checking qualitative data and helping shape the interpretation of quantitative data. Finally, the results should not only go into journal articles, but also into community action plans and materials that resonate with the people who contributed the data in the first place.

D. Community-Engaged Research: A Less Intensive Alternative to CBPR

Using the community-based participatory research (CBPR) approach involves significant investments of time and other resources. Moreover, it may be difficult if one's institutional setting is not designed to support CBPR. Community-engaged research (CEnR) is a less-intensive alternative that may be attractive to researchers who want to involve the community but may not be able to use the full CBPR model. Many of the principles remain the same. The first step is to learn about the community. This may seem obvious, but it involves building relationships, getting to know the history, culture, and power structures, and understanding the norms and values. The second step is for researchers to share power and show respect. Researchers should listen carefully and be open to difficult conversations about power dynamics. Additionally, small steps like providing food for meetings and offering child care can go a long way to helping community members participate. The third step is to include partners in all phases of research. While CEnR does not require completely equal decision-making power between researchers and community members, the views and goals of the latter should be incorporated into the study plan and execution where possible. The final step is for community partners to be compensated fairly. Researchers conduct studies for a living and get paid for their work; community partners should be

afforded the same opportunity.³⁷ Engaging the community using these principles can help your project be more responsive to the community's needs as well as more successful in achieving your goals.

³¹ Williams, A.S., & Moore, S.M. (2011). Universal Design of Research: Inclusion of Persons with Disabilities in Mainstream Biomedical Studies. *Science Translational Medicine*, 3(82), 82cm12. <http://doi.org/10.1126/scitranslmed.3002133>.

³² Bickenbach, J.E. (2012). Introduction, Background, and History. In G.L. Albrecht (Ed.), *Disability Key Issues and Future Directions: Ethics, Law, and Policy*. Thousand Oaks, CA: Sage Publications.

³³ Israel, B.A., Schulz, A.J., Parker, E.A., & Becker, A.B. (1998). Review of Community-Based Research: Assessing Partnership Approaches to Improve Public Health. *Annual Review of Public Health*, 19, 173-202. Retrieved from <https://www.annualreviews.org/doi/pdf/10.1146/annurev.publhealth.19.1.173>.

³⁴ Brown, S.C. (2001). Methodological Paradigms that Shape Disability Research. In G.L. Albrecht, K.D. Seelman, and M. Bury (Eds.), *The Handbook of Disability Studies*. Thousand Oaks, CA: Sage Publications.

³⁵ D'Alonzo, K.T. (2010 July 11). Getting Started in CBPR: Lessons in Building Community Partnerships for New Researchers. *Nursing Inquiry*, Vol. 17, No. 4, pp. 282-288.

³⁶ D'Alonzo, K.T. (2010 July 11). Getting Started in CBPR: Lessons in Building Community Partnerships for New Researchers. *Nursing Inquiry*, Vol. 17, No. 4, pp. 282-288.

³⁷ Michener, L., Cook, J., Ahmed, S.M., Yonas, M.A., Coyne-Beasley, T., & Aguilar-Gaxiola, S. (2012). Aligning the Goals of Community-Engaged Research: Why and How Academic Health Centers Can Successfully Engage with Communities to Improve Health. *Academic Medicine*, 87(3), 285-291. <http://doi.org/10.1097/ACM.0b013e3182441680>.

VI. Recruitment Templates

General Outreach Templates and Best Practices

<http://www.ccts.uic.edu/content/recruitment-templates>

FDA Research Volunteer Brochure

http://go.uic.edu/FDA_Research_Volunteer_Brochure

Flyer Templates

Our Peers - Empowerment and Navigational Support for People with Disabilities

Brochure

<http://www.ccts.uic.edu/sites/default/files/uploads/Stamped%20OP-ENS%20Brochure%201.24.18-final.pdf>

Flyer

http://www.ccts.uic.edu/sites/default/files/uploads/Stamped%20OP-ENS%20Intervention%20Flyer_V4_clean%20-%20final.pdf

ScreenABLE

English:

http://www.ccts.uic.edu/sites/default/files/uploads/ScreenABLE%20Saturday%20ENGLISH_Final.pdf

Spanish

http://www.ccts.uic.edu/sites/default/files/uploads/ScreenABLE%20Saturday%20SPANISH_Final.pdf

Simplified Recruitment Language

http://go.uic.edu/Simplified_Recruitment_Language

Supporting Enrollment & Engagement in Clinical Research

<http://www.ccts.uic.edu/sites/default/files/uploads/Example%202.pdf>

VII. Community Engagement Resources

A. Local Organizations

Access Living

<https://www.accessliving.org/>

Advocates for Access

<http://www.advocatesforaccess.com/>

Anixter Center

<http://www.anixter.org/>

The Arc of Illinois

<https://www.thearcofil.org/>

Brain Injury Association of Illinois

<http://www.biail.org/>

Center for Disability & Elder Law (CDEL)

<https://www.cdela.org/>

Easy Access Chicago

<http://easyaccesschicago.org/>

Equip for Equality

<https://www.equipforequality.org/>

Family Resource Center on Disabilities

<https://frcd.org/>

Great Lakes ADA Center

<http://www.adagreatlakes.org/>

KEEN Chicago

<http://www.keenchicago.org/>

NAMI Chicago

<http://namichicago.org/en/home/>

Statewide Independent Living Council of Illinois

<https://silcofillinois.org/>

Thresholds

<http://www.thresholds.org/>

B. National Organizations

ADA National Network

<https://adata.org/>

American Association of People with Disabilities

<https://www.aapd.com/>

Disability Rights Education & Defense Fund

<https://dredf.org/>

Easter Seals

<http://www.easterseals.com/>

National Disability Rights Network (NDRN)

<http://www.ndrn.org/index.php>

National Disabled Students Union

<http://www.disabledstudents.org/>

National Organization on Disability (NOD)

<https://www.nod.org/>

VIII. Researchers and Centers at UIC and C3 Working on the Issue

Please note: This list is intended to be illustrative rather than exhaustive. For UIC, associate and full professors are listed; for other institutions, full professors are listed. Resources to find additional researchers include <https://projectreporter.nih.gov/reporter.cfm>, <https://clinicaltrials.gov/>, <https://www.researchgate.net/>, and <https://scholar.google.com/>.

A. UIC (College of Applied Health Sciences, multiple departments including Disability & Human Development, Physical Therapy, and Rehabilitation Sciences)

Alex Aruin, PhD

<https://ahs.uic.edu/physical-therapy/directory/aruin-alex/>

Fabricio Balcazar, PhD

<https://ahs.uic.edu/disability-human-development/directory/balcazar-fabricio-e/>

Lennard Davis, PhD

<https://ahs.uic.edu/disability-human-development/directory/davis-lennard/>

Bo Fernhall, PhD

<https://ahs.uic.edu/directory/fernhall-bo/>

Gay Girolami, PhD

<https://ahs.uic.edu/physical-therapy/directory/girolami-gay-l/>

Mark Grabiner, PhD

<https://ahs.uic.edu/kinesiology-nutrition/directory/grabiner-mark-d/>

Joy Hammel, PhD

<https://ahs.uic.edu/disability-human-development/directory/hammel-joy/>

Glenn Hedman, MS, MEng

<https://ahs.uic.edu/disability-human-development/directory/hedman-glenn/>

Tamar Heller, PhD

<https://ahs.uic.edu/disability-human-development/directory/heller-tamar/>

Kueifang (Kelly) Hsieh, PhD

<https://ahs.uic.edu/disability-human-development/directory/hsieh-kueifang-kelly/>

Sarah Parker Harris, PhD

<https://ahs.uic.edu/disability-human-development/directory/parker-harris-sarah/>

Susan Magasi, PhD

<https://ahs.uic.edu/occupational-therapy/directory/magasi-susan/>

Sangeetha Madhavan, PhD

<https://ahs.uic.edu/physical-therapy/directory/madhavan-sangeetha/>

Shane Phillips, PhD

<https://ahs.uic.edu/physical-therapy/directory/phillips-shane/>

Patricia Ann Politano, PhD

<https://ahs.uic.edu/disability-human-development/directory/politano-patricia-ann/>

Carrie Sandahl, PhD

<https://ahs.uic.edu/disability-human-development/directory/sandahl-carrie/>

Yolanda Suarez-Balcazar, PhD

<https://ahs.uic.edu/disability-human-development/directory/suarez-balcazar-yolanda/>

Sandy Sufian, PhD

<https://ahs.uic.edu/disability-human-development/directory/sufian-sandy/>

Renee Taylor, PhD

<https://ahs.uic.edu/occupational-therapy/directory/taylor-renee/>

Annette L. Valenta, DrPH

<https://ahs.uic.edu/biomedical-health-information-sciences/directory/valenta-annette-l/>

Kiyoshi Yamaki, PhD

<https://ahs.uic.edu/disability-human-development/directory/yamaki-kiyoshi/>

B. Northwestern

Carol Courtney, PhD

<http://www.feinberg.northwestern.edu/faculty-profiles/az/profile.html?xid=42446>

Center for Autism and Neurodevelopment, Feinberg School of Medicine

<http://www.feinberg.northwestern.edu/sites/autism-neurodevelopment/>

Roxelyn and Richard Pepper Department of Communication Sciences and Disorders

<https://communication.northwestern.edu/departments/csd/research>

C. University of Chicago

Joseph P. Kennedy Jr. Intellectual and Developmental Disabilities Research Center

https://www.uchicago.edu/research/center/Joseph_P_Kennedy_Jr_Intellectual_and_Developmental_Disabilities_Research

IX. Measuring Instruments

A. Instruments for Use with People with Disabilities

Assessment for Persons with Intellectual Disability—The interRAI ID
<https://deepblue.lib.umich.edu/bitstream/handle/2027.42/75618/j.1741-1130.2006.00094.x.pdf?sequence=1&isAllowed=y>

Behavior Problems Inventory: An Instrument for the Assessment of Self-Injury, Stereotyped Behavior, and Aggression/Destruction in Individuals with Developmental Disabilities
<https://link.springer.com/content/pdf/10.1023/A:1013299028321.pdf>

Disability Assessment for Dementia Scale
<https://www.ncbi.nlm.nih.gov/pubmed/11391090>

Disability Assessment Scale (post-stroke)
<https://doi.org/10.1053/apmr.2002.35474>

Experiences of Discrimination (EOD) Measure
<https://doi.org/10.1016/j.socscimed.2005.03.006>

Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID)
<http://proxy.cc.uic.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=106851957>

Groningen Activity Restriction Scale
[https://doi.org/10.1016/S0277-9536\(96\)00057-3](https://doi.org/10.1016/S0277-9536(96)00057-3)

Impact on Participation and Autonomy Questionnaire
<https://doi.org/10.1053/apmr.2001.18218>

Kinesthetic and Visual Imagery Questionnaire (KVIQ) for Assessing Motor Imagery in Persons with Physical Disabilities
<http://doi.org/10.1097/01.NPT.0000260567.24122.64>

Liebowitz Social Anxiety Scale
<https://doi.org/10.1016/j.janxdis.2003.10.004>

Pain Disability Assessment Scale
<https://www.ncbi.nlm.nih.gov/pubmed/21178590>

Participation Survey/Mobility (PARTS/M)
<https://doi.org/10.1016/j.apmr.2005.09.014>

Perceived Discrimination

https://campus.fsu.edu/bbcswebdav/institution/academic/social_sciences/sociology/Reading%20Lists/Mental%20Health%20Readings/Kessler-HealthSocial-1999.pdf

Sex Knowledge, Experience, and Needs Scales for People with Intellectual Disabilities (SexKen-ID), People with Physical Disabilities (SexKen-PD), and the General Population (SexKen-GP)

[https://doi.org/10.1016/S0891-4222\(99\)00007-4](https://doi.org/10.1016/S0891-4222(99)00007-4)

World Health Organization Disability Assessment Scale (WHODAS II)

<http://www.ingentaconnect.com/contentone/mjl/sreh/2012/00000044/00000009/art00007?crawler=true&mimetype=application/pdf>

B. Instruments for Use with Others (family members, health care providers, etc.)

Attitude Toward Disabled Persons

<http://doi.org/10.1097/01.mrr.0000210048.09668.ab>

Beach Center Family Quality of Life Scale

<https://www.jstor.org/stable/pdf/4122894.pdf>

Contact With Disabled Persons Scale

<http://journals.sagepub.com/doi/pdf/10.1177/0034355207311310>

Multidimensional Attitudes Scale Toward Persons With Disabilities (MAS)

<http://journals.sagepub.com/doi/pdf/10.1177/00343552070500030401>

Multidimensional Scale of Perceived Social Support

<https://doi.org/10.1080/13668250600561929>

Vanderbilt ADHD Diagnostic Parent Rating Scale

<https://doi.org/10.1093/jpepsy/jsg046>

X. Program Announcements for Grants

The grants programs below either expire no earlier than 2019, or have ongoing postings about new grant opportunities.

National Institutes of Health (NIH)

Agency for Health Care Policy and Research (AHCPR) Research Grant Supplements for Individuals with Disabilities

<https://grants.nih.gov/grants/guide/notice-files/not94-076.html>

Assistive Technology for Persons with Alzheimer's Disease and Related Dementias and Their Caregivers (R41/R42 Clinical Trial Optional)

<https://grants.nih.gov/grants/guide/pa-files/PAR-18-587.html>

Development of Socially-Assistive Robots (SARs) to Engage Persons with Alzheimer's Disease (AD) and AD-Related Dementias (ADRD), and their Caregivers (R41/R42 Clinical Trial Optional)

<https://grants.nih.gov/grants/guide/pa-files/PAR-18-185.html>

Global Brain and Nervous System Disorders Research Across the Lifespan (R01)

<https://grants.nih.gov/grants/guide/pa-files/PAR-17-314.html>

Identification and Management of Behavioral Symptoms and Mental Health Conditions in Individuals with Intellectual Disabilities (R01 - Clinical Trial Optional)

<https://grants.nih.gov/grants/guide/pa-files/PAR-18-766.html>

NCI Mentored Research Scientist Development Award to Promote Diversity (K01 - Clinical Trial Required)

<https://grants.nih.gov/grants/guide/pa-files/PAR-18-365.html>

NCI Transition Career Development Award to Promote Diversity (K22 No Independent Clinical Trials)

<https://grants.nih.gov/grants/guide/pa-files/PAR-18-366.html>

Outcome Measures for Use in Treatment Trials of Individuals with Intellectual and Developmental Disabilities (R01 Clinical Trial Optional)

<https://grants.nih.gov/grants/guide/pa-files/PAR-18-039.html>

Preclinical Research on Model Organisms to Predict Treatment Outcomes for Disorders Associated with Intellectual and Developmental Disabilities (R01)

<https://grants.nih.gov/grants/guide/pa-files/PAR-16-215.html>

Pregnancy in Women with Disabilities (R01)

<https://grants.nih.gov/grants/guide/pa-files/PA-17-452.html>

Reducing Health Disparities Among Minority and Underserved Children (R01 Clinical Trial Optional)

<https://grants.nih.gov/grants/guide/pa-files/PA-18-152.html>

Research Supplements for Individuals with Disabilities

<https://grants.nih.gov/grants/guide/notice-files/not97-228.html>

Resource-Related Research Projects in the Epidemiology and Prevention of Pediatric Injury (R24)

<https://grants.nih.gov/grants/guide/pa-files/PAR-17-228.html>

Short-Term Research Education Program to Increase Diversity in Health-Related Research (R25
Clinical Trial Not Allowed)

<https://grants.nih.gov/grants/guide/rfa-files/RFA-HL-19-024.html>

Disability and Rehabilitation Research Projects (DRRP) Program

<https://www.grants.gov/web/grants/search-grants.html?cfda=93.433>

Paralyzed Veterans of America Research Foundation

<https://www.pva.org/research-foundation>

XI. Community Stakeholder Involvement

A. Disability Specific Resources

College of Applied Health Sciences

Disability and Human Development Department
<https://ahs.uic.edu/disability-human-development/>

Rehabilitation Sciences Department
<https://ahs.uic.edu/rehabilitation-sciences/>

Research Labs and Centers (Examples: Center for Capacity Building on Minorities with Disabilities Research, Family Support Research and Training Center, Sexuality and Disability Consortium)
<https://ahs.uic.edu/research/research-labs-and-centers>

Disability Cultural Center
<http://dcc.uic.edu/>

Disability Resource Center
<http://drc.uic.edu/>

Institute on Disability and Human Development
<https://ahs.uic.edu/disability-human-development/institute-on-disability-and-human-development/>

Office for Access and Equity: Disability Resources
<http://oe.uic.edu/resources/disability-resources/>

B. General Resources for Individuals

National Institutes of Health – Clinical Research Trials & You
<https://www.nih.gov/health-information/nih-clinical-research-trials-you/basics>

Research Fundamentals for Activists
<http://www.treatmentactiongroup.org/sites/default/files/201305/RFA%20FINAL.pdf>

Research Match (search for clinical trials to join)
<https://www.researchmatch.org/>

C. General Resources for Organizations

Alliance for Research in Chicagoland Communities, Northwestern University

Assessing your Organization's Research Environment and Capacity

<http://arccresources.net/wp-content/uploads/2013/08/Assessing-your-Organizations-Research-Environment-Capacity.pdf>

Community-Based Participatory Research 101

<http://arccresources.net/wp-content/uploads/2014/01/CBPR-101-2014expanded.pdf>

Community-Engaged Research Funding & Grantwriting Tips and Strategies

<http://arccresources.net/wp-content/uploads/2015/01/CEnRFunding.GrantwritingTips.Strategies.pdf>

Community Partner Resources

<http://arccresources.net/category/community-partners/>

Considering and Developing Your Organization's Research Purpose

<http://arccresources.net/wp-content/uploads/2013/08/Considering.Developing-Your-Organization%E2%80%99s-Research-Purpose.pdf>

Introduction to Qualitative Research Methods

<http://arccresources.net/wp-content/uploads/2015/09/Intro-to-Qualitative-Research-Methods.pdf>

Introduction to Research Design

<http://arccresources.net/wp-content/uploads/2013/08/Intro-to-Research-Design.pdf>

NIH Biosketch for Community Partner

<http://arccresources.net/wp-content/uploads/2015/06/NIH-Biosketch-for-Community-Partner.pdf>

Patient and Stakeholder Engagement (PCORI)

<http://arccresources.net/wp-content/uploads/2013/12/Patient-and-Stakeholder-Engagement-in-Patient-Centered-Outcomes-Research-PCORI.pdf>

University 101

<http://arccresources.net/wp-content/uploads/2014/12/University-101full.pdf>

Center for Clinical and Translational Sciences

<http://www.ccts.uic.edu/>

Recruitment, Retention, and Community Engagement Program

<http://www.ccts.uic.edu/content/recruitment-retention>

Clinical Trials Database

<https://clinicaltrials.gov/>

Community Based Participatory Research 101: From a Community Partner Perspective
Harlem Community & Academic Partnership

<https://ccph.memberclicks.net/assets/Documents/CNREI/cbpr%20101%20presentation.pdf>

A Quick Start Guide to Conducting Community-Engaged Research
Southern California Clinical and Translational Science Institute, Office of Community Engagement

http://oprs.usc.edu/files/2013/01/Comm_Engaged_Research_Guide.pdf

UIC Office of Community Engaged Research and Implementation Science

<https://cancer.uillinois.edu/outreach-program>

UIC Office of Community Engagement and Neighborhood Health Partnerships

<https://oceanhp.uic.edu/>

XII. Team Readiness to Work with Special Populations

A. Cultural competency training

Cultural Competence Assessment Instrument (CCAI)

<http://ccbmdr.ahslabs.uic.edu/wp-content/uploads/sites/5/2014/04/CCAI.pdf>

National Research and Training Center (NRTC) Training and Education: Toolkit and Training on Assessing Cultural Competency in Peer-Run Mental Health Programs

<http://www.cmhsrp.uic.edu/nrtc/starcenter.asp>

B. Team diversity representation

Making sure that the research team has some representation of the target special population group helps establish trust, understanding, and credibility. For example, when conducting research with Access Living, having people with disabilities as team members can help to build trust and understanding between the research team and community members. This step, however, is not sufficient by itself: other efforts described elsewhere in this toolkit should also be used to garner community support and involvement.

C. Implicit-association test (IAT) – Offers a way to probe unconscious biases

Implicit Association Test (IAT)

<http://projectimplicit.net/nosek/iat/>

Look Different's Implicit Association Tests

<http://www.lookdifferent.org/what-can-i-do/implicit-association-test>

Project Implicit

<https://implicit.harvard.edu/implicit/>

D. LH-STEP – Helps assess an individual's capabilities by measuring skills, abilities, and potential for success.

http://www.creativeorgdesign.com/tests_page.php?id=477

E. Resources to Evaluate Attitudes Necessary for Working with People with Disabilities

Attitude Toward Disabled Persons

<http://doi.org/10.1097/01.mrr.0000210048.09668.ab>

Contact With Disabled Persons Scale

<http://journals.sagepub.com/doi/pdf/10.1177/0034355207311310>

Multidimensional Attitudes Scale Toward Persons With Disabilities (MAS)

<http://journals.sagepub.com/doi/pdf/10.1177/00343552070500030401>

Citing the CCTS's Target Population Toolkit

The People with Disabilities Target Population Toolkit was developed by the UIC Center for Clinical and Translational Science's Recruitment, Retention and Community Engagement Program.

The National Institutes of Health requires that investigators cite the CTSA grant if they used any CCTS services or resources to support their research. The CCTS relies on these citations as a critical performance measure when reporting annual productivity to NIH.

To cite the CCTS, the following text is recommended:

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