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I. Historical and Current Issues Regarding Research Population

A. Contested Definitions

Older adults? Seniors? Elderly? Geriatrics?

Shifting conceptions of what it means to be older, role in society

Also, increasing diversity, implications for working with older adults

B. Theories of Older Age

Are there theories? Or just definitions?

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

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.¹ 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

Despite the array of health conditions facing older adults, they are less likely to be enrolled in clinical trials and other research. Participation becomes increasingly unlikely as age increases, with adults over the age of 75 far less likely to participate in research (citation).

F. Multiple Sources of Identity

An individual who is an older adult should be viewed in the context of multiple identities. In addition to their age, 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

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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.² See Section V, Recruitment and Retention Best Practices, for further information.

¹ 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>.

² 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](#)

[Cancer Screening: Reducing Structural Barriers for Clients – Colorectal Cancer](#)

[Epilepsy Across the Spectrum: Promoting Health and Understanding](#)

[The Future of Disability in America – Institute of Medicine Report](#)

[Interventions for improving employment outcomes for workers with HIV](#)

[Interventions to improve return to work in depressed people](#)

[Organizing healthcare services for persons with an intellectual disability](#)

[Vaccination Programs: Home Visits to Increase Vaccination Rates](#)

[Worksite: Seasonal Influenza Vaccinations Using Interventions with On-Site, Free, Actively Promoted Vaccinations – Healthcare Workers](#)

B. Searchable Database:

[Healthy People 2030 Best Practice Research Search](#)

III. National and Local Data

A. General Data

Pew Research Center

- [7 Facts about Americans with Disabilities](#)
- [Disability in the Digital Age](#)
- [Disabled Americans are Less Likely to Use Technology](#)
- [A Political Profile of Disabled Americans](#)

US Census Bureau

- [Aging-Accessible Homes \(Visualization\)](#)
- [Americans With Disabilities: 2010](#)
- [Disability among the Working Age Population: 2008 and 2009](#)
- [Disability Characteristics of Income-Based Government Assistance Recipients in the United States: 2011](#)
- [The Disability of Veterans](#)
- [Educational Attainment in the United States: 2015](#)
- [Employment Status and Occupations of Gulf War-Era Veterans](#)
- [How Common Are Specific Disabilities by Age? \(Visualization\)](#)
- [Older Americans with a Disability: 2008–2012](#)
- [Our Nation's Veterans - Distribution of Civilian Veterans, 18 Years and Over in the United States and Puerto Rico](#)
- [Prevalence of Disabilities for Ages 18+ \(Visualization\)](#)
- [The Relationship Between Health Conditions and the Core Disability Question Set](#)
- [The Research Supplemental Poverty Measure: 2012](#)
- [School-Aged Children With Disabilities in U.S. Metropolitan Statistical Areas: 2010](#)
- [Understanding Changes in the Disability Prevalence in the 2014 Survey of Income and Program Participation: Three Explanations Considered](#)

[CDC Wonder](#)

[Disability Statistics](#)

[National Council on Disability Transportation Update: Where We've Gone and What We've Learned](#)

B. State and Local Data

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

[City of Chicago: Facts and Figures about People with Disabilities in Chicago and the U.S.](#)

[Cornell University: 2016 Disability Status – Illinois](#)

[Greater Chicago Food Depository: Food Insecurity among Adults with Disabilities in Cook County – Realities and Remedies](#)

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

US Census Bureau

- [Chicago Quick Facts](#)
- [Illinois Quick Facts](#)

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.”³ 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.⁴ This has been incorporated into the UN Convention on the Rights of Persons with Disabilities.⁵ However, the U.S. has signed but not ratified this treaty, meaning it has essentially no power in this country.⁶ 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 <https://research.uic.edu/compliance/human-subjects-irbs/policies/>.

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.⁷ 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

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or condition, to improve functioning, or to create conditions that allow for greater participation regardless of functioning?⁸ 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.

³ 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.

⁴ 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>.

⁵ 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.

⁶ Helderan, 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.

⁷ Metrics: Disability-Adjusted Life Year (DALY). (2018). *World Health Organization*. Retrieved from http://www.who.int/healthinfo/global_burden_disease/metrics_daly/en/.

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.

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).⁹

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.”¹⁰ 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.¹¹ 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].¹² 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*

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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.¹³ 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.¹⁴ 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.¹⁵ 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.

⁹ 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>.

¹⁰ 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.

¹¹ 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>.

¹² 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.

¹³ 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.

¹⁴ 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.

¹⁵ 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

[CCTS CEC Recruitment Templates Toolbox](#)

VII. Community Engagement Resources

A. Local Organizations

[Access Living](#)

[Advocates for Access](#)

[Anixter Center](#)

[The Arc of Illinois](#)

[Brain Injury Association of Illinois](#)

[Center for Disability & Elder Law \(CDEL\)](#)

[Easy Access Chicago](#)

[Equip for Equality](#)

[Family Resource Center on Disabilities](#)

[Great Lakes ADA Center](#)

[KEEN Chicago](#)

[NAMI Chicago](#)

[Statewide Independent Living Council of Illinois](#)

[Thresholds](#)

B. National Organizations

[ADA National Network](#)

[American Association of People with Disabilities](#)

[Disability Rights Education & Defense Fund](#)

[Easter Seals](#)

[National Disability Rights Network \(NDRN\)](#)

[National Organization on Disability \(NOD\)](#)

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](#)

Alex Aruin, PhD, is a faculty member in the Department of Physical Therapy at the University of Illinois at Chicago. His profile highlights his research interests, publications, and expertise in the areas of motor control and rehabilitation. Dr. Aruin's work focuses on understanding and improving human movement in individuals with neurological disorders.

[Fabricio Balcazar, PhD](#)

Fabricio Balcazar, PhD, is a faculty member in the Department of Disability and Human Development at the University of Illinois at Chicago. His profile showcases his research interests, publications, and expertise in disability studies and community inclusion. Dr. Balcazar's work aims to promote social justice and improve the lives of individuals with disabilities through research, policy, and practice.

[Lennard Davis, PhD](#)

Lennard Davis, PhD, is a faculty member in the Department of Disability and Human Development at the University of Illinois at Chicago. His profile highlights his research interests, publications, and expertise in disability studies and cultural studies. Dr. Davis explores the social and cultural constructions of disability, challenging stereotypes and advocating for disability rights.

[Gay Girolami, PhD](#)

Gay Girolami, PhD, is a faculty member in the Department of Physical Therapy at the University of Illinois at Chicago. Her profile showcases her research interests, publications, and expertise in the areas of movement disorders and neurorehabilitation. Dr. Girolami's work focuses on improving functional outcomes and quality of life for individuals with neurological conditions.

[Mark Grabiner, PhD](#)

Mark Grabiner, PhD, is a faculty member at the University of Illinois at Chicago. His expertise lies in the field of biomechanics and his research focuses on understanding the control and coordination of human movement, particularly in older adults. Dr. Grabiner's work has implications for fall prevention and mobility enhancement in aging populations.

[Joy Hammel, PhD](#)

Joy Hammel, PhD, is a faculty member in the Department of Disability and Human Development at the University of Illinois at Chicago. Her profile highlights her research interests, publications, and expertise in the areas of community participation and social inclusion for individuals with disabilities. Dr. Hammel's work aims to promote full participation and equal opportunities for people with disabilities in all aspects of society.

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[Glenn Hedman, MS, MEng](#)

Glenn Hedman, MS, MEng, is a faculty member in the Department of Disability and Human Development at the University of Illinois at Chicago. His profile showcases his research interests, publications, and expertise in the areas of assistive technology and accessible design. Mr. Hedman's work focuses on developing innovative solutions to enhance accessibility and improve the lives of individuals with disabilities.

[Tamar Heller, PhD](#)

Tamar Heller, PhD, is a faculty member in the Department of Disability and Human Development at the University of Illinois at Chicago. Her profile highlights her research interests, publications, and expertise in the areas of disability policy and services. Dr. Heller's work aims to promote inclusive policies and support systems that empower individuals with disabilities.

[Kueifang \(Kelly\) Hsieh, PhD](#)

Kueifang (Kelly) Hsieh, PhD, is a faculty member in the Department of Disability and Human Development at the University of Illinois at Chicago. Her profile showcases her research interests, publications, and expertise in the areas of aging and disability, long-term care, and health disparities. Dr. Hsieh's work focuses on addressing the unique challenges faced by older adults with disabilities.

[Sarah Parker Harris, PhD](#)

Sarah Parker Harris, PhD, is a faculty member in the Department of Disability and Human Development at the University of Illinois at Chicago. Her profile highlights her research interests, publications, and expertise in the areas of disability policy and advocacy. Dr. Harris's work aims to improve the lives of individuals with disabilities through policy analysis, community engagement, and advocacy efforts.

[Susan Magasi, PhD](#)

Susan Magasi, PhD, is a faculty member in the Department of Occupational Therapy at the University of Illinois at Chicago. Her profile showcases her research interests, publications, and expertise in the field of occupational therapy. Dr. Magasi's work focuses on assessing and improving the quality of life of individuals with disabilities through the development and validation of measurement tools and interventions.

[Sangeetha Madhavan, PhD](#)

Sangeetha Madhavan, PhD, is a faculty member in the Department of Physical Therapy at the University of Illinois at Chicago. Her profile highlights her research interests, publications, and expertise in the areas of global health, aging, and disability. Dr. Madhavan's work focuses on understanding the social, cultural, and environmental factors that influence health and well-being across different populations.

[Shane Phillips, PhD](#)

Shane Phillips, PhD, is a faculty member in the Department of Physical Therapy at the University of Illinois at Chicago. His profile showcases his research interests, publications, and expertise in the areas of musculoskeletal health and pain. Dr. Phillips' work aims to improve the understanding and management of musculoskeletal conditions, with a focus on optimizing rehabilitation outcomes and promoting physical activity.

[Patricia Ann Politano, PhD](#)

Patricia Ann Politano, PhD, is a faculty member in the Department of Disability and Human Development at the University of Illinois at Chicago. Unfortunately, the provided link is to her curriculum vitae (CV) rather than a profile. The CV provides an overview of Dr. Politano's academic and professional background, including her research interests, publications, and contributions to the field of disability and human development.

[Carrie Sandahl, PhD](#)

Carrie Sandahl, PhD, is a faculty member in the Department of Disability and Human Development at the University of Illinois at Chicago. Her profile showcases her research interests, publications, and expertise in the areas of disability arts and culture. Dr. Sandahl's work explores the intersection of disability, performance, and activism, focusing on the transformative power of the arts in challenging societal perceptions and promoting inclusivity.

[Yolanda Suarez-Balcazar, PhD](#)

Yolanda Suarez-Balcazar, PhD, is a faculty member in the Department of Disability and Human Development at the University of Illinois at Chicago. Her profile highlights her research interests, publications, and expertise in the areas of community health promotion and disability studies. Dr. Suarez-Balcazar's work focuses on promoting social inclusion and participation of individuals with disabilities through community-based interventions and empowerment strategies.

[Sandy Sufian, PhD](#)

Sandy Sufian, PhD, is a faculty member in the Department of Disability and Human Development at the University of Illinois at Chicago. Her profile showcases her research interests, publications, and expertise in the areas of disability studies and health disparities. Dr. Sufian's work explores the social and cultural aspects of disability, as well as the intersections of disability and healthcare.

[Renee Taylor, PhD](#)

Renee Taylor, PhD, is a faculty member in the Department of Occupational Therapy at the University of Illinois at Chicago. Her profile highlights her research interests, publications, and expertise in the field of occupational therapy. Dr. Taylor's work focuses on promoting independence, well-being, and quality of life for individuals with disabilities through occupational therapy interventions and research.

[Annette L. Valenta, DrPH](#)

Annette L. Valenta, DrPH, is a faculty member in the Department of Biomedical and Health Information Sciences at the University of Illinois at Chicago. Her profile showcases her research interests, publications, and expertise in the areas of health informatics and health disparities. Dr. Valenta's work aims to improve healthcare outcomes and reduce disparities through the application of health informatics and technology.

[Kiyoshi Yamaki, PhD](#)

Kiyoshi Yamaki, PhD, is a faculty member in the Department of Disability and Human Development at the University of Illinois at Chicago. His profile highlights his research interests, publications, and expertise in the areas of assistive technology and disability policy. Dr. Yamaki's work focuses on the development and implementation of innovative assistive technologies to enhance the independence and well-being of individuals with disabilities.

B. Northwestern

[Carol Courtney, PhD](#)

Carol Courtney, PhD, is a faculty member at the Feinberg School of Medicine, Northwestern University. Her profile on the Feinberg School of Medicine website provides an overview of her academic and professional background, research interests, and publications. Dr. Courtney's work focuses on the intersection of communication sciences and disorders with an emphasis on speech-language pathology.

[Center for Autism and Neurodevelopment, Feinberg School of Medicine](#)

The Center for Autism and Neurodevelopment at the Feinberg School of Medicine, Northwestern University, is dedicated to advancing research, education, and clinical care for individuals with autism and other neurodevelopmental disorders. The center's website provides information about their programs, faculty, research initiatives, and resources for individuals and families affected by autism and neurodevelopmental conditions.

[Roxelyn and Richard Pepper Department of Communication Sciences and Disorders](#)

The Roxelyn and Richard Pepper Department of Communication Sciences and Disorders at Northwestern University offers comprehensive academic programs in the field of communication sciences and disorders. Their website provides information about faculty, research, clinical services, and educational opportunities in the field of speech-language pathology and audiology.

C. University of Chicago

[Joseph P. Kennedy Jr. Intellectual and Developmental Disabilities Research Center](#)

The Joseph P. Kennedy Jr. Intellectual and Developmental Disabilities Research Center is a research center at the University of Chicago dedicated to advancing knowledge and improving the lives of individuals with intellectual and developmental disabilities. The center's website provides information about their research projects, faculty, training programs, and resources for individuals and families affected by intellectual and developmental disabilities.

IX. Measuring Instruments

A. Instruments for Use with People with Disabilities

[Assessment for Persons with Intellectual Disability—The interRAI ID](#)

[Behavior Problems Inventory: An Instrument for the Assessment of Self-Injury, Stereotyped Behavior, and Aggression/Destruction in Individuals with Developmental Disabilities](#)

[Disability Assessment for Dementia Scale](#)

[Disability Assessment Scale \(post-stroke\)](#)

[Experiences of Discrimination \(EOD\) Measure](#)

[Glasgow Anxiety Scale for people with an Intellectual Disability \(GAS-ID\)](#)

[Groningen Activity Restriction Scale](#)

[Impact on Participation and Autonomy Questionnaire](#)

[Kinesthetic and Visual Imagery Questionnaire \(KVIQ\) for Assessing Motor Imagery in Persons with Physical Disabilities](#)

[Liebowitz Social Anxiety Scale](#)

[Pain Disability Assessment Scale](#)

[Participation Survey/Mobility \(PARTS/M\)](#)

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

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

[Attitude Toward Disabled Persons](#)

[Beach Center Family Quality of Life Scale](#)

[Contact With Disabled Persons Scale](#)

[Multidimensional Attitudes Scale Toward Persons With Disabilities \(MAS\)](#)

[Multidimensional Scale of Perceived Social Support](#)

[Vanderbilt ADHD Diagnostic Parent Rating Scale](#)

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](#)
- [Assistive Technology for Persons with Alzheimer's Disease and Related Dementias and Their Caregivers \(R41/R42 Clinical Trial Optional\)](#)
- [Development of Socially-Assistive Robots \(SARs\) to Engage Persons with Alzheimer's Disease \(AD\) and AD-Related Dementias \(ADRD\), and their Caregivers \(R41/R42 Clinical Trial Optional\)](#)
- [Global Brain and Nervous System Disorders Research Across the Lifespan \(R01\)](#)
- [Identification and Management of Behavioral Symptoms and Mental Health Conditions in Individuals with Intellectual Disabilities \(R01 - Clinical Trial Optional\)](#)
- [NCI Mentored Research Scientist Development Award to Promote Diversity \(K01 - Clinical Trial Required\)](#)
- [NCI Transition Career Development Award to Promote Diversity \(K22 No Independent Clinical Trials\)](#)
- [Outcome Measures for Use in Treatment Trials of Individuals with Intellectual and Developmental Disabilities \(R01 Clinical Trial Optional\)](#)
- [Preclinical Research on Model Organisms to Predict Treatment Outcomes for Disorders Associated with Intellectual and Developmental Disabilities \(R01\)](#)
- [Pregnancy in Women with Disabilities \(R01\)](#)
- [Reducing Health Disparities Among Minority and Underserved Children \(R01 Clinical Trial Optional\)](#)
- [Research Supplements for Individuals with Disabilities](#)
- [Resource-Related Research Projects in the Epidemiology and Prevention of Pediatric Injury \(R24\)](#)
- [Short-Term Research Education Program to Increase Diversity in Health-Related Research \(R25 Clinical Trial Not Allowed\)](#)

[Disability and Rehabilitation Research Projects \(DRRP\) Program](#)

[Paralyzed Veterans of America Research Foundation](#)

XI. Community Stakeholder Involvement

A. Disability Specific Resources

College of Applied Health Sciences

- [Disability and Human Development Department](#)
- [Rehabilitation Sciences Department](#)
- [Research Labs and Centers \(Examples: Center for Capacity Building on Minorities with Disabilities Research, Family Support Research and Training Center, Sexuality and Disability Consortium\)](#)

[Disability Cultural Center](#)

[Disability Resource Center](#)

[Institute on Disability and Human Development](#)

[Office for Access and Equity: Disability Resources](#)

B. General Resources for Individuals

[National Institutes of Health – Clinical Research Trials & You](#)

[Research Fundamentals for Activists](#)

[Research Match \(search for clinical trials to join\)](#)

C. General Resources for Organizations

[Assessing your Organization’s Research Environment and Capacity](#)

[Community-Based Participatory Research 101](#)

[Community-Engaged Research Funding & Grantwriting Tips and Strategies](#)

[Community Partner Resources](#)

[Considering and Developing Your Organization’s Research Purpose](#)

[Introduction to Qualitative Research Methods](#)

[Introduction to Research Design](#)

[NIH Biosketch for Community Partner](#)

[Patient and Stakeholder Engagement \(PCORI\)](#)

[University 101](#)

[Center for Clinical and Translational Sciences](#)

- [Recruitment, Retention, and Community Engagement Program](#)

[Clinical Trials Database](#)

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

[UIC Office of Community Engaged Research and Implementation Science](#)

[UIC Office of Community Engagement and Neighborhood Health Partnerships](#)

XII. Team Readiness to Work with Special Populations

A. Cultural competency training

[Cultural Competence Assessment Instrument \(CCAI\)](#)

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

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 \(IAT\)](#)

[Look Different's Implicit Association Tests](#)

[Project Implicit](#)

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

[Attitude Toward Disabled Persons](#)

[Contact With Disabled Persons Scale](#)

[Multidimensional Attitudes Scale Toward Persons With Disabilities \(MAS\)](#)

Citing the CCTS's Target Population Toolkit

The Older Adults 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:

“The University of Illinois at Chicago Center for Clinical and Translational Science is supported by the National Center for Advancing Translational Sciences, National Institutes of Health, through Grant UL1TR002003. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.”

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