INTERAGENCY COMMITTEE ON
DISABILITY RESEARCH

Interagency Committee on Disability Research (ICDR)
Virtual Stakeholder Meeting:

Inclusion of People with Disabilities across Federal Disability and Rehabilitation Research

Summary Report

Wednesday, June 28, 2023 — 12:00 p.m. – 4:00 p.m. ET

Welcome

Rasheda Parks, Ph.D., Executive Director, Interagency Committee on Disability Research (ICDR)

Dr. Rasheda Parks welcomed the ICDR Executive Committee members, panelists, presenters, and stakeholders to the 3rd Annual ICDR Stakeholder Meeting. She reviewed the meeting's agenda, which included a stakeholder panel discussion on strategies to engage people with lived experience to help inform the federal research agenda; presentations on emerging topics in rehabilitation research; breakout sessions focusing on COVID-19, equity, and disability data and statistics; and federal agency discussions on various programs and initiatives that benefit the disability and rehabilitation community. Dr. Parks then introduced the keynote speaker, Wendy Strobel Gower.

Opening Remarks

Wendy Strobel Gower, M.S., Thomas P. Golden Director of Disability-Inclusive Workplaces and Employer Fee-for-Service Initiatives, K. Lisa Yang and Hock E. Tan Institute on Employment and Disability, Cornell University

Following her introduction, Ms. Wendy Strobel Gower described her numerous roles in various agencies by expounding on each agency's key focus areas and their contribution to disability research.

As Co-Director of the Employer Assistance and Resource Network on Disability Inclusion (EARN), which is funded by the Office of Disability Employment Policy (ODEP), Ms. Strobel Gower has the opportunity to work with federal partners and agencies as they implement the executive order of Diversity, Equity, Inclusion, and Accessibility (DEIA) in the federal workforce. And through the Federal Exchange on Employment & Disability (FEED), they have witnessed employees supporting programs that help increase the participation and success of federal employees with disabilities, as well as agencies striving to better meet their needs.

Ms. Strobel Gower is also the Director of the Northeast ADA Center, which focuses on capacity building - such as helping to move ADA implementation out into the world - through focused work and targeted areas, and by training community leaders and advocates who work on these issues. The outcomes make the time and effort worthwhile, but the impact of can be difficult to measure. To address this issue, Ms. Strobel Gower shared how her research team at the Northeast ADA Center is applying a new capacity building measure called Ripple Effect Mapping, which will provide participants with an opportunity for reflection. They will update NIDILRR annually on this new measuring tool.

As the President of NARRTC, Ms. Strobel Gower shared they have been focusing on the impact of NIDILRR grantees' work. The policy, practice, and behavioral changes that have resulted from their work have prompted the organization to think about how they conduct research, deliver services, and measure the results. It is not just about learning new things and sharing information; it is also about ensuring that the information shared is understood by the audience and can be applied to communities and workplaces. As the focus is placed more heavily on impact, it will be important to ensure all federally-funded grantees are contributing to the science of knowledge translation, making it easier for community groups to contribute to research and resources - to move disability and inclusion forward.

Ms. Strobel Gower closed by thanking the ICDR for all the work that they do to make sure that federal departments and agencies work together to advance the inclusion of people with disabilities.

Stakeholder Panel Discussion: Engaging People with Lived Experience to Inform the Federal Research Agenda

Moderator: Theresa Hayes Cruz, Ph.D., Director, National Center for Medical Rehabilitation Research (NCMRR), National Institutes of Health

Panelists:

- *Gyasi Burks-Abbott, M.S., Faculty, Leadership Education in Neurodevelopmental and related Disabilities (LEND) Program, Boston Children's Hospital, Faculty, University of Massachusetts Boston's Institute for Community Inclusion*
- *James Meadours, President, Peoples First of Oklahoma, Chair, Self Advocates Becoming Empowered, President, Texas Advocates*
- *Katherine McDonald, Ph.D., Associate Dean of Research and Professor of Public Health, Falk College of Sport and Human Dynamics, Syracuse University*
- *Ariel Schwartz, Ph.D., Research Assistant Professor, Institute on Disability, University of New Hampshire*

Question #1 - Introduction: Can you tell us about your journey? If you are a person with a disability and you feel comfortable in identifying yourself as such, please describe how that has impacted the work you do.

Mr. Gyasi Burks-Abbott is on the autism spectrum; he was diagnosed when he was 17 years old. He pursued a double major in college and began doing research on autism as part of his psychology major. This led him to get involved in various organizations in Minnesota, and he continued his work and involvement in different organizations after moving to Massachusetts - where he has been for the last 25 years.

Mr. James Meadours has been involved with the advocacy movement for 34 years. He shared how exciting it has been to see the progress over the years for individuals with intellectual disabilities.

Dr. Ariel Schwartz collaborates with individuals with disabilities. From the very beginning of her career, Dr. Schwartz has been motivated to do research that is inclusive of the disability community.

Dr. Katherine McDonald does work related to health, wellbeing, and community participation for individuals with disabilities, and partners with them to get them more involved in research projects - either as a research partner or participant. Growing up among family members and close friends with disabilities, Dr. McDonald paid attention to and was concerned about how they were treated and the opportunities they had or did not have. Her commitment to furthering the goals of equity and social justice for individuals with disabilities gave rise to her work - to include more people with disabilities through research and collaborations.

Question #2 - Research Participation: Have you been a participant in research or helped to get other people with disabilities involved in research? What are you doing in your research to make it more inclusive for people with disabilities?

Mr. Burks-Abbott shared that over the years he has participated in several focus groups and studies. For example, he participated in MRI studies at MIT, was involved in several studies at the Patient-Centered Outcomes Research Institute (PCORI), and collaborated on research articles with faculty and students. He hopes that researchers will come to realize that participants are intellectually curious and want to meaningfully participate studies and learn about the results.

Mr. Meadours has been working with Strategic Education Solutions to help people get the support they need and was subsequently hired to recruit more self-advocates. They received a new three-year grant from the Texas Developmental Disabilities Council because they wanted to make it easier for individuals with intellectual and developmental disabilities (IDD) to get more involved in research. Mr. Meadours shared how they created self-advocacy tools designed to help researchers include more people with IDDs in their research.

Dr. Cruz thanked Mr. Meadours and highlighted several points: the importance of having individuals with disabilities regularly participate in research studies, tools are being developed to help researchers be more inclusive of individuals with disabilities, and researchers should consider paid participation for their participants with lived experience and community partners as they put together their research budgets.

Dr. McDonald has done a lot of collaborative research with people with disabilities. Whether it is a research project, focus group or individual interview, she offered several guidelines to help ensure the inclusivity of people with disabilities

- Maintain long-term mutual relationships with people with disabilities to help inform the science/research.
- Go in with an anti-ableist mindset and continuously overturn assumptions about people with disabilities. It is important to be aware of ableist mindsets and how choice can be taken away - regardless of whether researchers are working collaboratively with people with disabilities or including them in as research participants.
- Make sure that the materials and processes being used are both respectful and accessible.
    - Study the views of people with disabilities on how they want to be included in research and build responsive practices around those views.
    - Use language that reflects the population’s preferences (e.g., person-first language vs. identity-first language).
    - Recruit participants in trusted channels. Demonstrate that the research is credible (e.g., backed by federal support) and help reduce their concerns to make it as easy as possible for people with disabilities to participate in research studies.

- Make sure to acknowledge collaborators with disabilities on publications and presentations.
- Reflect on the research practice by asking: What are we doing? How are we doing it? Was it respectful? Was it accessible? What could have been done better? By asking questions and obtaining feedback, researchers can continue to refine their research practice.

Dr. Schwartz emphasized how doing research in partnership with people with disabilities not only leads to more valid research, but also enhances the overall trust within the disability community. She offered additional guidelines for how to augment partnerships with people with disabilities in the research process.

- Identify the team members' roles at the beginning. For example, the colleague with lived experience can be the driver behind developing research questions, and others with shared expertise in other areas of the research can share the role of decision-making. Defining these roles and thinking about lived experiences at the onset can help the team be more mindful about respect, accessibility, and inclusion as they consider survey designs and focus group approaches.
- Help people with disabilities take ownership of their research contributions. If decisions are made based on the team members with disabilities' input, help them understand the impact they are having on the work. Maintaining openness, transparency and explicit communication of their contributions is critical for building trust and ownership.

Question #3 - Difficult Conversations: Can you talk about what difficult conversations the disability research agenda needs to discuss before progress can be made? Are there any difficult conversations that researchers must have with each other?

Mr. Burks-Abbott expressed how many difficult conversations on disability research revolve around how the results of the research agenda get implemented. In many cases, researchers cannot implement something even though they know it will work because of limited funding. An example of this is living in a community vs. an institutional setting. People have better outcomes living in a community than in institutional settings, but there are long waiting lists because of the workforce crisis. This is partly due to a lack of funding and a desire to cut costs. There is always a desire to decrease spending and balance the budget, but the questions that need to be asked are: At whose expense? What are our values? Why are some things considered an investment and other things considered an expense? The difficult conversation that needs to take place should address what we value and what we are willing to put our money towards.

Mr. Meadours shared several difficult conversation topics. He encouraged everyone to talk about sexual assault directly because people with IDD are at an increased risk of experiencing it. He also emphasized helping people with disabilities and their family members/guardians address the fear of losing Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) benefits. Mr. Meadours shared how a lot of people decide not to work on research projects because they and/or their parents are afraid of losing SSI/SSDI benefits. While it is important to support those with disabilities who want to work, it is also important to explain to their parents/guardians who are afraid of their child losing benefits as a result.

Dr. McDonald encouraged everyone to read a report published by the National Institutes of Health (NIH) working group on individuals with disabilities. The report serves as a template for how researchers can analyze, reflect, and refine how they do research. It prompts researchers to ask how they can build communities of practice so they are not duplicating one another's efforts, but acting in collaboration and coordination toward a shared goal – high-quality science that improves lives.

Dr. Schwartz talked about the importance of discussing the inclusion and exclusion of people with disabilities in research, and proposed advancing policies and practices that would require federal funded researchers to justify when they are excluding people with disabilities as a broader federal agenda. She shared two studies that identified how people with disabilities are often excluded from scientific research because of antiquated thoughts around their capacity to consent and the presumption that disability may impact the scientific process. When setting up the exclusion and inclusion criteria, if there a lack of scientific rationale for excluding people with disabilities, they should not be excluded. This lack of inclusion of people with disabilities across the entire span of research topics results in significant health and wellness disparities. The questions that need to be asked are: Why are you choosing to exclude people with disabilities from your study? Is this a barrier that we can resolve? What are the collaborations that need to be implemented so that all research includes disability?

Dr. Cruz reiterated Dr. Schwartz's points by emphasizing just how important it is to get actively involved in the recruitment process and understand what additional steps need to be taken to get people with disabilities more involved in the research process. This will ultimately help make the research more impactful and generalizable.

Question #4 - Future: What are your dreams? Where do you want to see us all go?

Mr. Burks-Abbott shared the Surgeon General recently issued an advisory about an epidemic of loneliness, which also addresses plans to mobilize the healthcare sector so providers are ready to assess patients at risk of loneliness and intervene. People with disabilities are more likely to lack connections and experience social isolation and Mr. Burks-Abbott hopes the strategy will include people with disabilities and help them become more integrated into their communities as researchers and citizens.

Mr. Meadours hopes more researchers will pay their participants with disabilities fair wages, not gift cards; use plain language to help increase everyone's understanding of the project; hire a support person who can offer additional assistance when needed; allow participants with disabilities to be more involved in the research process from beginning to end; and give participants with disabilities meaningful work. This will help people with disabilities realize they are a valued team player with a lot to contribute.

Dr. McDonald shared her dream is to see a vibrant disability research community that learns from one another and is inclusive of people with disabilities and has strong investments from federal and other funders.

Adding to what Dr. McDonald shared, Dr. Schwartz emphasized how building a workforce of people with disabilities in research will require clear career pathways and funding structures and processes that will promote these career pathways. A sustainable pathway must be created to further support and sustain researchers and their research.

Q&A and Discussion

How do we get more principal investigators (PIs) with disabilities involved in research?

Mr. Meadours suggested reaching out to local self-advocacy groups to find individuals interested in a specific research topic/project.

Mr. Burks-Abbott suggested looking beyond the traditional qualifications for a PI to include those who have potential but may not have the necessary degrees or publications traditionally expected of PIs.

Dr. McDonald shared how they have a co-PI model, which includes a person who is scientifically trained and another person who has lived experience, and they both share equal authority over the project. Dr. McDonald also suggested reaching out to high schools through HR, academic programs or mentoring programs to help get more people with disabilities excited about pursuing a scientific career path.

Dr. Schwartz suggested elevating traditionally unpaid mentorship roles to careers paths for people with disabilities to support this emerging workforce.

Before closing out the panel discussion, Dr. Cruz noted that there were two areas of interest that were not covered during the panel discussion but mentioned in the chat box: interactions with tribal communities and COVID-19.

Presentations: Emerging Topics in the Field of Disability and Rehabilitation Research

Moderator: Amanda Reichard, Ph.D., Project Officer, National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), Administration for Community Living (ACL), U.S. Department of Health and Human Services

Presentation #1: Impact of Therapy Caps in Health Insurance

Sam Porritt, M.B.A., Chairman, Falling Forward Foundation

Mr. Porritt is a Steering Committee Member of the Coalition to Preserve Rehabilitation (CPR), which consists of more than 50 national consumer, clinician and membership organizations that advocate for policies to ensure people will be able to access rehabilitative care. Mr. Porritt explained what therapy caps are, their impact on patient outcomes and healthcare costs, and how they can be ended through increased research. Therapy encompasses physical, occupational and speech therapy/language pathology - things that can help people recover and rebuild the functions and abilities they lost due to an acquired disability.

Therapy caps refer to the limit on how much outpatient rehabilitation health programs and plans will provide, regardless of medical necessity. The most common therapy cap found in health plans is the 30-visit limit on outpatient rehabilitation. Because of this one-size-fits-all approach, the patient will only receive a maximum of 30 visits to outpatient rehabilitation, regardless of whether they sprained their ankle or broke every bone in their body.

Medicare first imposed therapy caps in 1997, and commercial insurers soon followed. While Medicare caps were repealed by statute in 2018, virtually all commercial plans still institute some sort of therapy cap. The impact of this is significant because therapy caps can limit full recovery potential.

- Millions of Americans incur neurological injuries (e.g., stroke, traumatic brain injury, etc.) every year. The recovery process is slow and long, and 30 visits will not be enough.
- Various disabilities and conditions lead people to need extended rehabilitation, but they must stop receiving therapy when they reach their cap. As a result, most people do not fully recover/improve and get as much function back as they could have without the cap.
- Maintaining and not going backwards on function/strength are all critical to recovery. Some people need rehab to maintain the abilities they have achieved, but this can be thwarted by therapy caps.

Mr. Porritt shared his own personal recovery journey. While he and his wife were on vacation in Italy in 2011, Mr. Porritt stood too close to a wall while taking a picture, and he fell. He suffered a spinal cord injury and was paralyzed from the bellybutton down. Mr. Porritt received two years of rehab and learned how to stand and walk on his own. He had that chance because his insurance policy did not have a therapy cap.

Mr. Porritt shared that he still wears braces on his ankles because they have limited strength, but he is able to walk and do many things he would not have been able to do if not for the rehab he received. If he had a therapy cap, a lot of this would not be possible for him. This is why he is so passionate about therapy caps and why he hopes to get more people interested in helping address this issue that impacts millions of people every year.

Mr. Porritt proposed several areas of research:

- Assess differences in outcomes (e.g., functional measures, independence, etc.) between rehab participants with and without therapy caps.
- Refine "dosing" of recommended therapy intensity, duration, and scope to achieve optimal outcomes. This moves away from the one-size-fits-all approach and moves toward finding the right rehab for the best possible outcome. A person with a knee injury may only need 30 visits to recover, but a person with a neurological injury will need X-number of visits to recover.
- Assess differences in longer-term healthcare costs (e.g., readmission, ongoing nursing care, institution-based care, sequelae of sedentary lifestyle, etc.) between rehab participants with and without therapy caps. This takes into consideration the societal long-term costs of people not fully recovering. There is a short-term cost to doing rehab, but does it offset decades of long-term costs if the person gets the rehab up front?
- Identify opportunities for collaboration across federal agencies to address this issue.

Q&A and Discussion

Do you have any strategies to challenge the insurance therapy cap?

Assessing differences in longer-term healthcare costs (e.g., readmission, ongoing nursing care, institution-based care, sequelae of sedentary lifestyle, etc.) between rehab participants with and without therapy caps. Therapy caps allow insurance companies to avoid short-term costs (e.g., paying for another 50 sessions of rehab), but as a result of avoiding that short-term cost upfront, the long-term costs add up (e.g., hospital Readmissions, ongoing nursing care, etc.). Assessing these long-term costs will show the insurers that if they pay for rehabilitation up front, they will have a greater long-term profit.

It is not just rehabilitation, but habilitation and habilitative services are also capped. Can you comment on that as well?

Habilitative care is necessary to maintain function, quality of life and independence.

What are advocacy groups doing to create stronger regulations on commercial carriers?

Mr. Porritt shared how CPR is working on addressing the therapy cap issue. The first breakthrough was in 2018 when Medicare changed its policy, but not much has progressed in getting commercial insurers to change. To his knowledge, CPR is the only group that is actively talking about addressing the therapy cap issue with commercial insurers, and they are interested in forming collaborations to tackle this issue together.

Presentation #2: The Value of Using Disability Data to Facilitate Disability Inclusion

Andrew Houtenville, Ph.D., Professor of Economics and Research Director, Institute on Disability, University of New Hampshire

Dr. Andrew Houtenville discussed ways disability data can be used to facilitate disability inclusion. In terms of direct opportunities for inclusion related to disability statistics, Dr. Houtenville suggested the following areas where it is crucial to include people with disabilities: production of disability data (e.g., determining themes of a survey, designing the survey questionnaire, recruiting sample members); analysis of disability data (e.g., designing analytical plan such as "table shells," generating necessary statistics); dissemination findings (e.g., presenting/co-presenting, authoring/co-authoring publication); and evaluation of process and impact (e.g., designing evaluation plan, collecting data, summarizing results).

In regards to the inclusion of people with disabilities in research, Dr. Houtenville highlighted two main areas: inclusion as subjects and/or proxy responses (i.e., head of household, guardian, etc.) and inclusion of people with disabilities as part of the entire research process. Dr. Houtenville explained that NIDILRR has consistently added more information about the inclusion of people with disabilities within its research criterion. For example, NIDILRR asks how the design of the research activities are informed by input from people with disabilities and other key stakeholders. He mentioned this is an important area he looks for in his experience as a reviewer for NIDILRR. Dr. Houtenville expressed that his view of this topic is greatly informed by NIDILRR's continued elevation of this effort in its grant competitions.

Indirect opportunities for inclusion of people with disabilities in research include: utilization (e.g., using disability statistics in advocacy, self-advocacy, communications) and advocacy for better disability data (e.g., pushing for an Annual Disability Survey, pushing for inclusion of disability questions in specific surveys, such as the Consumer Expenditure Survey).

Dr. Houtenville emphasized that ultimately the inclusion of people with disabilities is a necessity. He discussed that language often used in research focuses on the "need" or the "problem." He suggested that using a social justice lens may change the language that we use to talk about inclusion. As an example, Dr. Houtenville described his work with Kessler Foundation and how they developed the concept of "striving to work" rather than "underemployment" to be more empowering when discussing employment for people with disabilities. People with disabilities and the disability community have a fundamental right to disability statistics that accurately reflect and represent their self-identities, portray their identities to others in an unbiased manner, and inform the policies and programs that impact their lives. People with disabilities must be an integral part of every data collection effort and research/knowledge translation teams. Capacity building is a fundamental part of this. Dr. Houtenville highlighted two important examples of capacity building in this area: SSA's Analyzing Relationships between Disability, Rehabilitation and Work (ARDRAW) program and NIDILRR's Advanced Rehabilitation Research and Training (ARRT) program.

Q&A and Discussion

How would you say researchers are doing in terms of 1) awareness of existing data resources (not simply datasets from other studies but things like epicenters, Medicaid & Medicare, post-claims data, ACL's AGID database, etc.), especially in communities of color and 2) understanding tribal data sovereignty?

In terms of capacity, there is a large amount existing data and many innovative ways to use it. Talking to people on the ground can help inform creative ways to use the existing data. However, there are also major limits around existing data, especially in relation to data security and privacy.

In terms of multiply marginalized groups, national datasets have issues with obtaining adequate sample sizes for more rare populations. It is also important to consider whether the questions being asked are culturally relevant and translated appropriately.

Dr. Reichard said that the ICDR will soon be publishing a toolkit on disability statistics that will be a great resource for referencing what federal datasets exist for investigating disability and rehabilitation related topics. Additionally, the ICDR Disability Statistics Subcommittee is working on raising awareness, not just among researchers, but also among federal staff, about including disability identifiers in datasets and understanding why this is important. Dr. Reichard agreed that with national samples, the sample sizes to examine intersectionality are often too small. While no solutions for this currently exist, it is encouraging that this topic is being discussed regularly now and elevated as an important issue to address.

Do you have suggestions for how to better include people with moderate to severe IDD who are excluded from datasets?

Dr. Houtenville cited the Survey of Income and Program Participation data, which has a category for IDD, but lumps it together with learning disabilities. He suggested that in order to address this, sample size must increase to better view this category of people with IDD.

He also discussed if using Medicaid data to examine people with IDD, researchers end up missing people with IDD who do not qualify for Medicaid, often those with better outcomes since their higher income disqualifies them from the program. By using any non-probability-based approach to sampling people within rare groups, it is important to examine what bias you are introducing. For example, if a membership is used, this could introduce significant bias by "sampling from the choir." From his own experience, it could be helpful to focus on how centers and grantees form their advisory committees. For example, is it representative of the general public in terms of geography or other important factors.

Agency Panel Discussion: Optimizing Inclusion of People with Disabilities in Federal Research Activities

Moderator: Susan A. Daniels, Ph.D., National Autism Coordinator, Department of Health and Human Services, Director, Office of National Autism Coordination, National Institute of Mental Health, Executive Secretary, Interagency Autism Coordinating Committee (IACC)

Phillip Beatty, Director, Office of Research Sciences, National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS)

Dr. Phillip Beatty presented an overview of the scope of the disability and rehabilitation research that NIDILRR funds. NIDILRR's mission is to generate new knowledge and promote its effective use to improve the abilities of individuals with disabilities to perform activities of their choice in the community and to expand society's capacity to provide full opportunities and accommodations for people with disabilities. NIDILRR has a budget of $119 million dollars and funds research and development, capacity building, and knowledge translation. NIDILRR's three outcome domains are: health and function, community living and participation, and employment. NIDILRR sponsors disability and rehabilitation research that examines populations across the lifespan and is cross-disability.

Dr. Beatty also provided a summary of several NIDILRR initiatives to include people with disabilities in the work that it sponsors. NIDILRR regularly hires people with disabilities onto its federal team, including both at the staff level and on the NIDILRR management team. NIDILRR also recruits people with disabilities to serve on its peer review panels. Inclusion of people with disabilities has been a strong NIDILRR practice and has been increasingly prioritized in recent years. NIDILRR aims to have at least one person with a disability on each panel, and to measure implementation of this, they administer a short survey to all peer reviewers. NIDILRR requires inclusion of people with disabilities on grant teams. Applicants are required to specify in their proposal the way that people with disabilities will be included as part of the proposed research and development teams and how their input will be incorporated into grant activities. Dr. Beatty discussed how the input of people with disabilities is included as peer review criteria, both in relation to research design and to recruitment of project staff. NIDILRR also monitors if grantee teams include people with disabilities as part of its annual performance report. Based on the data collected, hundreds of paid staff and dozens of principal investigators are people with disabilities. Lastly, Dr. Beatty discussed how NIDILRR is very conscious of the language that it uses to refer to people with disabilities in agency documents. He provided several examples of how certain terms can have implied power differentials and how other terms can invite collaboration.

Timothy Brindle, Ph.D., Scientific Program Manager, Rehabilitation Research & Development Service, Veterans Administration

Dr. Timothy Brindle presented a program overview of the disability and rehabilitation research portfolio in the Office of Research and Development (ORD) at Veterans Affairs (VA). The VA Health Care System is an integrated health care system with a research program that serves over 9 million veterans and has over 200,000 clinical employees. While the number of veterans is decreasing, the number of Veterans with disabilities continues to increase. The ORD focuses on the three "Rs": restoring injured organs/tissues, replacing that which cannot be restored, and returning mind-body function, family, employment, and community engagement to enable veterans to function fully in the environment/society. The scientific program areas of rehabilitation research and development include: behavioral health and social reintegration (19%), brain health and injury (19%), rehabilitation engineering (prosthetics/orthotics) (14%), sensory systems and communication disorders (13%), spinal cord injury/disorders and pain (13%), chronic medical conditions and aging (11%), musculoskeletal health and function (10%), and regenerative rehabilitation (5%). Dr. Brindle then reviewed several criteria for VA funding eligibility and program aspects.

Dr. Brindle discussed several current efforts aimed at inclusion of people with disabilities in research, including three programs related to DEI efforts at VA: Minority Serving Institution Career Development Award; ORD Summer Research Program; and ORD research supplements to support diversity. Next, Dr. Brindle described one of RR&D's special emphasis areas, "health disparities and conditions that impact underserved veterans within the context of understanding the onset, severity, duration, rehabilitation, and recovery from disability." Dr. Brindle also described the efforts of several specific research centers. For example, the Center for Wheelchairs and Assistive Robotics Engineering (WARE) works "to promote professional development opportunities and grow future leaders that reflect the diversity of the Veterans VA serves." This center's space is designed to be an exemplary model workspace for research and for inclusion of veterans with disabilities in the workforce. Dr. Brindle invited participants to reach out to him with any questions about any of the efforts discussed in his presentation.

Alison Cernich, Ph.D., Deputy Director, Eunice Kennedy Shriver National Institute of Child Health and Human Development, National Institutes of Health

Dr. Alison Cernich discussed disability and rehabilitation research activities at NIH and provided an overview of the mission of the National Center for Medical Rehabilitation Research (NCMRR) to foster development of scientific knowledge needed to enhance the health, productivity, independence, and quality of life of people with physical disabilities. NCMRR is the NIH lead for rehabilitation and assistive technology research and coordinates across NIH to facilitate research. NCMRR leads the National Advisory Board on Medical Rehabilitation Research, leads development of NIH Research Plan on Rehabilitation, supports the Medical Rehabilitation Research Resource Network, leads the Rehabilitation Research Training and Career Development, and coordinates the Rehabilitation Research Speaker Series. Funding for the category "rehabilitation" in the overall NIH research portfolio has steadily grown from $500 million in 2015 to $800 million in 2021. Dr. Cernich provided highlights of recent disability and rehabilitation related research at NIH. She explained that the NIH is trying to move away from the medical model of disability and focus not just on co-morbid conditions, but also on health and wellness and optimal functioning for people with disabilities. She recommended the following recent NIH workshops related to disability: Workshop on Inclusive Participation in Clinical Research (NIMHD), Disability and Genomics in the Past, Present, and Future (NHGRI), Cerebral Palsy Workshop (NINDS/NICHD), Neuro-urology Workshop (NIDDK), and Presentation on Amputee Resources in Low and Middle Income Countries (FIC/NCMRR).

Dr. Cernich discussed the need for improved NIH efforts to include people with disabilities in research and identified several factors that lead to underrepresentation in research, such as ableism, use of the medical model, etc. Some of the areas NIH is working to transform include: education about and experience with people with disabilities; universal design and compliance with new rules on accessibility; identification and reduction of barriers (transportation, consent/information accessibility), provision of education, resources, training, and targeted outreach to principal investigators, and provision of education on resources for principal investigators with disability for career and science. In line with these goals, Dr. Cernich described an approved concept for an upcoming funding opportunity on Health Disparities Experienced among Persons Living with Disabilities. Dr. Cernich highlighted a recent workshop hosted by NCMRR, Ableism in Medicine and Clinical Research Workshop (Day 1 recording link; Day 2 recording link). This workshop was aimed at raising awareness of ableism in both clinical care and the biomedical and behavioral research enterprise and to identify research opportunities to mitigate the effect of ableism. Dr. Cernich concluded by saying that NIH will soon announce a funding opportunity designed to encourage research to understand the impact of ableism.

Mark Leddy, Ph.D., Program Director, Division of Equity for Excellence in STEM (EDU/EES), National Science Foundation

Dr. Mark Leddy emphasized that the National Science Foundation's (NSF) is committed to diversity and deems it central to its programs, projects, and activities. He discussed several initiatives to include people with disabilities in research. NSF has policies and procedures to support people with disabilities who need accommodations during the proposal process, available in NSF's proposal and award policies and procedures guide. Additionally, NSF asks panelists and proposal reviewers to disclose if they have a disability as part of their demographic profiles to conduct data driven planning and ultimately to improve accessibility at NSF. NSF also has policies and procedures to support accommodations for applicants during the hiring process and for NSF federal employees. Dr. Leddy discussed two NSF employee resource groups, one on accessibility and one on mental health. Additionally, NSF's National Center for Science and Engineering Stats conducts periodic national surveys and publishes a biannual report to assess the current STEM employment and education standing of people with disabilities, women, and people from racial and ethnic minority groups. Over a decade ago, NSF established facilitation awards for scientists and engineers with disabilities to reduce or remove barriers to research and training and encourage pursuit of careers in STEM.

NSF put out a new call for proposals to the Workplace Equity for Persons with Disabilities in STEM and STEM Education solicitation. Dr. Leddy also mentioned two NSF "Dear Colleague" letters, which are used to direct proposers to NSF programs that welcome proposals: Persons with Disabilities – STEM Engagement and Access and Research to Improve STEM Teaching, Learning, and Workforce Development for Persons with Disabilities. NSF funds numerous grants related to people with disabilities, including The Alliance for Students with Disabilities for Inclusion, Networking, and Transition Opportunities in STEM and Beyond Compliance: Workplace Barriers, Access, and Inclusive Policies Impacting People with Disabilities in the STEM Workforce. Dr. Leddy described five major programs in NSF's Directorate for Engineering Activities that fund rehabilitation research: Disability and Rehabilitation Engineering, Broadening Participation in Engineering, Mind, Machine and Motor Nexus, Engineering of Biomedical Systems, and Biomechanics and Mechanobiology. Last December, NSF's

Convergence Accelerator awarded $11,800,000 to 16 teams to develop solutions to enhance quality of life and employment opportunities for persons with disabilities. The last initiative Dr. Leddy discussed is the AI Institute for Transforming Education for Children with Speech and Language Processing Challenges, which is working towards universal speech and language screening for children. He directed those interested in more information to NSF's Broadening Participation webpage.

Closing Remarks

Anjali J. Forber-Pratt, Ph.D., Director, National Institute on Disability, Independent Living, and Rehabilitation Research, Administration for Community Living, Department of Health and Human Services

Dr. Anjali Forber-Pratt thanked the presenters, moderators, and attendees for engaging in robust conversation and dialogue during the meeting. The vision of the meeting was to center the lived experiences of people with disabilities and highlight approaches to foster better inclusion in research.

Dr. Forber-Pratt expressed excitement that these conversations about inclusion are happening. As a researcher who is a disabled, woman of color, she said that role models of researchers with disabilities did not exist when she was going through graduate school or was in principal investigator roles. In her own research lab prior to her current role, her lab became a place for disabled individuals who wanted to be involved in research and build a community of practice. Including disabled researchers made their research better and filled the need for those seeking out an inclusive research community. She is thrilled to be leading NIDILRR and the ICDR now in her current role so that conversations like the ones during this meeting can help the field work together to tackle hard questions and operationalize these ideas in federal grantmaking procedures.

"Nothing about us without us," a famed mantra in the disability community, also includes research. During the meeting, many examples of what this means were shared, including considering the types of questions asked, who is on the research teams, etc. It is also important to ensure the diversity of experiences that occur across the disability community are captured. Dr. Forber-Pratt concluded by saying she is grateful to be having these conversations and encouraged stakeholders to continue to collaborate and leverage connections with experts and resources.

Dr. Rasheda Parks thanked everyone for attending the 3rd Annual ICDR Stakeholder Meeting. She hopes the information presented helps to further inform the disability research community. She encouraged attendees to visit the ICDR website and register for the listserv to be notified about upcoming events and activities.