



Equity: More than a Seat at the Table
2023 Annual Conference & Business Meeting
 April 25-26, 2023
 Ritz-Carlton - Pentagon City, Arlington, VA
 Register at narrtc.org

President's Message

Hello NARRTC Members!



Wendy Stroble Gower
 Yang Tan Institute on
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Wendy is the Project Director of the
 Northeast ADA Regional Center
www.northeastada.org

Spring is upon us at last. Now that more and more people are traveling, we are hoping to see many of you at our annual conference. We are excited to host NIDILRR's new equity centers to learn more about the equity center's plans for these new centers. We have also extended invitations to NIDILRR for their customary update panel as well as a technical assistance panel. Andre Washington, our VP, has put together a great couple for days for us!

NARRTC is once again seeking nominations to serve. Look at our open positions and think about how you can contribute.

- The President-Elect role is available for a one-year term. At the end of the year, you will become president of NARRTC, and I will transition to the role of past president in support of the new president. The president-elect role gives you time to learn and grow into the role of president. It is an honor to represent your fellow NIDILRR grantees, so I hope some of you will consider running. New representation brings new ideas and new life to our organization.

- We are also looking to fill the position of Vice President for a one-year term. We recognize that this role is challenging, as this person serves as our conference chair, and is essential to the success of our annual conference. Former VPs are able and willing to support the person who will fulfill this role. If you've ever thought NARRTC needs to spice up the conference or try something new, this position is the perfect launching pad for your ideas.
- The Secretary role is open for a three-year term. This position gives you a birds-eye view of all our meetings and activities and is responsible for sharing our activities with our members.
- Finally, we are seeking to fill two member-at-large positions for three-year terms. This is a great role to consider if you are new to executive council membership or a young professional.

Sitting on the NARRTC Executive Council affords you the opportunity to work closely with our funding agency and to get to know fellow grantees who are dedicated to highlighting the work our projects do. I know I have met some incredible people through my role in NARRTC. I encourage you to join us in service on the NARRTC Executive Council.

Thanks to Mark Odum, our communications committee chair, for pulling together this great newsletter! We look forward to catching up with you more frequently through its pages. See you in April!

Wendy Strobel Gower
 President, NARRTC



April 24, 2023, preNARRTC Workshop "Outreach to Policymakers"

Registration is open now for the "Outreach to Policymakers" workshop, hosted by the Center on KTDRR, Monday, April 24, 2023, at the NARRTC conference hotel, Ritz-Carlton, Pentagon City in Arlington, Virginia.

The workshop will run from 9:00 a.m. to 3:45 p.m. ET.

Mark Bayer of Bayer Strategic Consulting facilitates this interactive training. Learn about (and practice!) which strategies are best for sharing research information with state and national policymakers.

[View a video welcome from Mark Bayer.](#)

Click here for a [transcript](#) of the video.

Management Concepts will introduce the workshop with a short presentation describing restrictions on lobbying pertinent to federal grantees.

The workshop will culminate with a panel of former NIDILRR policy fellows discussing their experiences both during their fellowship and in their current positions, including **Dr. Anne Ordway** who is now a Program Specialist at NIDILRR.

Details and registration:

<https://ktdrr.org/training/workshops/2023outreach>

Note: The workshop is free and open to the public; however, registration is capped at 15 attendees. As of 3/23/23 there were 6 spaces left. We will give priority to NIDILRR grantees.

From the Legislative Committee

On December 9, 2022, the Advisory Committee to the Director (ACD) of the National Institutes of Health (NIH) unanimously endorsed a report and set of recommendations drafted by the Working Group on Diversity's Subgroup on Individuals with Disabilities. Subgroup co-chair, Bonnie Swenor, observes:

"People with disabilities are profoundly underrepresented in the biomedical and behavioral research workforce. Less than 2% of NIH-funded researchers have a disability. Ableism (i.e., discriminatory beliefs that people with disabilities are flawed and therefore less valuable than non-disabled people), bias, lack of accessibility accommodations, and other barriers prevent people with disabilities from participating fully in the scientific workforce. This landmark NIH report and set of recommendations have the potential to tackle these disparities."

The specific recommendations endorsed by the ACD are:

- Update the NIH mission statement to eliminate ableist language about "reducing disability."
- Establish an NIH Office of Disability Research to coordinate research activities involving people with disabilities and support disability inclusion within the scientific workforce.
- Ensure that disability inclusion and anti-ableism are core components of all NIH diversity, equity, inclusion, and accessibility (DEIA) efforts.
- Develop an internal, NIH-wide effort to identify and address structural ableism and promote disability inclusion, similar to approaches used to tackle other forms of discrimination.
- Expand efforts to include disability communities and the perspectives of individuals with disabilities in NIH efforts and help inform NIH approaches with these perspectives.
- Formally designating people with disabilities as a health disparity population, allowing for more funding of research addressing the health inequities disabled people face.

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Conference Preview: The Equity Centers

This plenary session will review the research and activities of three new equity centers in the National Institute on Disability, Independent Living, and Rehabilitation Research's (NIDILRR's) Rehabilitation Research and Training Center (RRTC) program.

They are the **Community Living Equity Center (CLEC)**, the **Langston University RRTC on Advancing Employment Equity for Multiply Marginalized People with Disabilities (LU2E-RRTC)**, and the **Advancing Health Equity for Adults with Disabilities from Marginalized Communities (AHEAD-MC) RRTC**.

NIDILRR's mission is to generate new knowledge and promote its effective use to support improvement in the major outcome domains of community living and participation, employment, and health and function.

These equity centers focus on reducing disparities in community living, employment, and health care experienced by people with disabilities from marginalized populations as defined by race, ethnicity, LGBTQIA+ status, poverty status, and rurality.

The **CLEC** aims to address knowledge gaps around community living and participation inequities and outcomes faced by disabled people of color. The CLEC will do this by creating interventions to address equity, leveraging existing and new data sources, developing new policy and systems-change initiatives, and through active dissemination of findings and trainings for stakeholders. The CLEC presenters will share details and information about research projects focused on the need, access, and utilization of home and community-based services by disabled people of color and our approach of participatory leadership of disability organizations and disabled individuals throughout the Center's work.

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Legislative (cont'd)

- Collecting data on disability wherever demographic information is collected within NIH data systems.
- Establishing structures of accountability around efforts to promote progress and transparency in all of these efforts.

The **Disability and Rehabilitation Research Coalition** (DRRC - a coalition of 25 national non-profit organizations, including NARRTC, who are committed to improving the science of disability, independent living, and rehabilitation) has actively supported the work of the Subgroup on Individuals with Disabilities, and is now working to educate policymakers in the White House and Congress about the importance of promptly implementing their recommendations.

Jae Kennedy, the chair of NARRTC's legislative committee, is heading a panel presentation on this topic at NARRTC's annual research meeting on April 26, 2023, with Dr. Bonnie Swenor (Johns Hopkins University), Dr. Jean Hall (University of Kansas), and Joe Nahra (DRRC lobbyist and Powers and Associates Director of Government Relations).



Did you know NARRTC has a job board?

We know how challenging it can be to find the best candidates for your research team. We also know the NIDILRR grantee community can be a great recruiting tool! Post your position announcements for 30, 60, or 90 days for free! Use code **2023MEMBER** when posting. Visit <https://narrtc.org/how-to-join/narrtc-job-board/> to learn more.

Equity (cont'd)

The LU2E-RRTC serves as a national resource center for advancing employment equity for multiply marginalized people with disabilities. The LU2E-RRTC will provide an overview of five major studies designed to reduce employment disparities and build the pool of available underrepresented researchers, especially those with disabilities. These studies will generate (1) a new Intersectional Framework for Employment Equity, (2) detailed information about intersectional disparities, (3) a new proof-of-concept prototype for a Multiply Marginalized Persons with Disabilities Small Business Incubator Model, (4) employment solutions for Native Americans/American Indians harmed by the opioid epidemic, and (5) individual profiles and service patterns for multiply marginalized youth with disabilities that contribute to their occupational stability.

Additionally, a brief overview of two new researcher pipeline mentoring programs in the form of the Visiting Disability and Rehabilitation Equity Researcher Mentorship Program and Native American/American Circles of Knowing initiatives will be discussed. The AHEAD-MC RRTC aims to address healthcare disparities experienced by individuals with physical, cognitive, sensory, and developmental disabilities from marginalized backgrounds. The AHEAD-MC RRTC will discuss three projects that will examine existing data and two that will develop and evaluate interventions designed to enhance access to care at either the individual or systems level. While all projects will include individuals with physical, cognitive, sensory, and developmental disabilities, analyses and development activities will be tailored to specifically identify factors that result in increased disparities among traditionally marginalized populations, and the system-change or policy recommendations to reduce disparities.



2023 Best Paper Awards

Jean Hall, Noelle Kurth, Catherine Ipsen, Andrew Myers, Kelsey Goddard:

Comparing Measures Of Functional Difficulty with Self-Identified Disability:

Implications for Health Policy. Health Affairs, Vol. 41, No. 10.

doi:10.1377/hlthaff.2022.00395. Open access.

2023

BEST PAPER

PUB 2022

The Affordable Care Act mandated data collection standards to identify people with disabilities in federal surveys to better understand and address health disparities within this population. Most federal surveys use six questions from the American Community Survey (ACS-6) to identify people with disabilities, whereas many international surveys use the six-item Washington Group Short Set (WG-SS). The National Survey on Health and Disability (NSHD), which focuses on working-age adults ages 18-64, uses both question sets and contains other disability questions. We compared ACS-6 and WG-SS responses with self-reported disability types. The ACS-6 and WG-SS failed to identify 20 percent and 43 percent, respectively, of respondents who reported disabilities in response to other NSHD questions (a broader WG-SS version missed 4.4 percent of respondents). The ACS-6 and the WG-SS performed especially poorly in capturing respondents with psychiatric disabilities or chronic health conditions. Researchers and policy makers must augment or strengthen federal disability questions to improve the accuracy of disability prevalence counts, understanding of health disparities, and planning of appropriate services for a diverse and growing population.

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Best papers (cont'd)

Conclusion: The findings from our study of federal surveys suggest that many people with psychiatric disabilities and chronic illnesses are not included in national estimates of disability. Thus, public funding for these populations may also be inappropriately low. In addition, broad functional categories, such as those used in the ACS-6 and WG-SS, that do not align with self-categorized primary disabilities add complexities to reporting. In the COVID-19 pandemic, people with many chronic illnesses and disabilities are at increased risk for adverse outcomes, yet understanding of the true prevalence of these conditions may be lacking. In addition, large numbers of people with long COVID may be overlooked. If both function- and condition-specific questions are included in these surveys, data can be used more reliably by researchers, policy makers, and practitioners to track prevalence and types of disabilities, create more supportive services and environments, understand health disparities, and address risks. Mounting evidence suggests that understanding and tracking disability at the national level can be improved, and the addition of a small complement of disability questions seems like a reasonable charge.

Erin Higgins, Michelle Zorrilla, Kathleen Murphy, Megan Robertson, Mary Goldberg, Susan Cohen, Nancy Augustine, Jonathan Pearlman: Barriers and facilitators to technology transfer of NIDILRR grantees. *Disability and Rehabilitation: Assistive Technology*. doi:10.1080/17483107.2022.2122604. Open access.

2023
FINALIST
PUB 2022

The objectives of this mixed-methods study were to gather survey and interview data about the barriers and facilitators from grantees funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) and to extract themes that could inform program changes that would increase technology translation (TT) success in assistive technology (AT). Across survey and interview respondents, the three most common themes when exploring the barriers and facilitators of TT were funding, incentives, and collaboration.

Judith Cook, Pamela Steigman, Margaret Swarbrick, Jane Burke-Miller, Taina Ling, Laurie Vite, Jessica Jonikas, Isaac Brown. Outcomes of Peer-Provided Individual Placement and Support Services in a Mental Health Peer-Run Vocational Program. *PS in Advance*. doi:10.1176/appi.ps.20220134.

2023
HONORABLE MENTIONS
PUB 2022

The authors sought to determine whether staff at a peer-run agency could deliver supported employment services with high fidelity to the individual placement and support (IPS) model and whether employment outcomes of peer-delivered IPS plus work-specific health promotion were superior to usual supported employment services. Providing training in IPS along with health promotion to the behavioral health peer workforce may help address the severe shortage of IPS services and enhance the competitive employment outcomes of people served by peer-run programs.

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Congratulations to the winners and honorable mentions! Register for the 2023 conference to hear their presentations.

Best papers (cont'd)

Michael DeVivo, Yuying Chen, Huacong Wen. Cause of Death Trends Among Persons With Spinal Cord Injury in the United States: 1960-2017. *Archives of Physical Medicine and Rehabilitation*, Vol. 104, No. 4. doi:10.1016/j.apmr.2021.09.019

To identify trends in causes of death after spinal cord injury (SCI) that could enhance understanding of why life expectancy after SCI has not improved in the last 3 decades. Conclusion; Improving life expectancy after SCI will require: (1) reducing mortality rates from respiratory diseases and septicemia that have remained high, (2) reversing current trends in diabetes and unintentional injury deaths, and (3) continuing to reduce mortality from heart disease and other leading causes.

Lisa Reber, Jodi Kreschmer, Tyler James, Jaime Junior, Gina DeShong, Shan Parker, Michelle Meade. Ableism and Contours of the Attitudinal Environment as Identified by Adults with Long-Term Physical Disabilities: A Qualitative Study. *International Journal of Environmental Research and Public Health*, Vol. 19, No. 12. doi:10.3390/ijerph19127469. Open access.

Adults with physical disabilities experience a continuum of enabling and disabling attitudes in the environment. This study identified where adults with physical disabilities experience the attitudinal environment, the continuum of those attitudes, and how they impact emotional and psychological health and well-being. Focus groups and interviews were conducted in 2019 and 2020 with adults with physical disabilities in southeastern Michigan in the United States. Participants discussed environmental factors that impact healthy aging. From an initial thematic coding of narratives, the attitudinal environment was identified. Transcripts were recoded and analyzed focusing on societal attitudes. Qualitative analyses revealed that participants did not experience societal attitudes as simply positive or negative, and that the contexts in which these attitudes were expressed were not limited to interpersonal interactions. Rather, these attitudes were also experienced in the built environment and through social institutions and organizations and their programs, systems, and structures that provide or deny needed accommodations, resources, and support. The spectrum of overlapping attitudes that participants articulated ranged from understanding and supportive, to not understanding, to being viewed and treated as less than human. Societal structures reflect and influence societal attitudes and have material consequences on the lives of adults with physical disabilities. This study identifies one of the fundamental challenges adults with physical disabilities experience: societal attitudes. Individuals, the built environment, and institutional structures produce societal attitudes that are felt. Greater awareness of how societal attitudes are manifested, and their material consequences lead to choices that can reduce ableism and the attitudinal environment. Attention to the attitudinal environment and the inclusion of socioeconomically and racially diverse populations will further our understanding of the challenges faced by a significant segment of society. The knowledge gained can help rehabilitation professionals understand that living successfully with a disability goes far beyond an individual's ability to manage their impairment and the emotional challenges that it may bring. The well-being of adults with physical disabilities is influenced by the attitudes they perceive in society, and this can impact the ability to live well with their disability. More broadly, it can inform policy makers about the barriers adults with physical disabilities encounter daily and the need for greater sociospatial justice.

From the Nominating Committee

This is a request for nominations for in-person elections to be held at the NARRTC Annual Meeting on April 25, 2023, at the Ritz-Carlton - Pentagon City, 250 S. Hayes St., Arlington, VA 22203.



Jae Kennedy, PhD
Chair, Nominating &
Legislative Committees

Member projects each have one vote per position, which can be cast by any project representative attending the conference. As the past-President and current chair of the Nominating Committee, I'd strongly encourage all NARRTC member projects to nominate one or more candidates to serve on the NARRTC Executive Committee. You don't have to be a project PI or co-I, and early or mid-career project members may even benefit more from this leadership experience. There isn't a ton of committee work for most of the year (other than a monthly Zoom call), though there is a flurry of activity in the winter and early spring to prepare for the annual conference. In general, it's a great opportunity to get to know other experienced NIDILRR grantees and to see them as potential mentors and colleagues, instead of competitors.

Please fill out and submit one form per position (available at narrtc.org), for which you wish to nominate a candidate. You can nominate the same person for more than one position, but make sure you submit separate forms for each position (if someone wins more than one office, the Nominating Committee will ask them which position they prefer). Self-nominations are encouraged, but if you want to nominate a project colleague, please make sure they are willing to serve before you mail in the form. Nominations will also be taken from the floor during the Annual Meeting.

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From the Communications Committee

This is your newsletter -
tell us what you'd like to see

We aim to publish NARRTC News on a quarterly basis and we want to know what types of content you'd like to see in future issues.

Upcoming issues may include

- Conference wrap up
- Distinguished, Commendation, and Special Service awards
- Member project profiles
- Legislative updates
- Opportunities to share your input to NIDILRR and other agencies supporting the full participation of people with disabilities in the community

If you have ideas for features, or would like to contribute to an upcoming issue, contact Mark Odum, Chair, Communications Committee at modum@heitechservices.com



Did you know your membership covers every member of your project's team?

NARRTC membership is project based. Every member of your project's team is eligible to receive organization benefits including:

- Discounted registration fees for the annual meeting and conference
- Awards programs
- Legislative and program updates
- Subscription to the NARRTC member listserv for important announcements.
- The NARRTC Job Board

Contact Jess Chaiken, Chair, Membership Committee, to check that everyone on your team can access these benefits!

Nominations (cont'd)

Honestly, we're still getting our feet under us after pandemic-related disruptions, so we have a lot of openings. We are specifically looking for candidates for the following positions:

1. President-Elect (1-year term, 2023-2024).

The President-Elect shall aid the President and other members of the Board of Governors and seek to obtain the greatest possible acquaintanceship with the membership affairs, individuals, and national trends, to enable effective transition to the Office of President when succession occurs after the Annual Meeting and Conference when the President's term expires.

2. Vice-President and Conference Program Chair (1-year term, 2023-2024)

This person should be a NARRTC member who is willing to lead a team of NARRTC colleagues to organize and conduct the next Annual Meeting of NARRTC (Spring 2023). The Program Chair has access to written materials on how to run the Meeting as well as has access to past Program Chairs for advice and guidance.

3. Secretary (3-year term, 2023-2026)

This person should be a NARRTC member who is willing to keep the membership informed of actions of the association, such as a record of the meetings and transactions of the general membership, the Board of Governors and the Executive Committee. Participates in one-hour monthly calls with the Executive Committee and takes minutes at the Annual Meeting.

4. Two Members-at-Large (3-year terms, 2023-2026)

These individuals should be NARRTC members. They may be new to the organization, looking to become more involved, or members of longer standing who are looking to become re-involved. They participate in one-hour monthly calls with the Executive Committee. Learn more in the By-Laws:

Please return the completed form(s) by April 17, 2023 to Jae Kennedy, Chair of the Nominating Committee: jjkennedy@wsu.edu. Please contact me by e-mail if you'd discuss these leadership opportunities, and I will be happy to follow up by e-mail, phone or Zoom.

Nomination forms are online at <https://tinyurl.com/NARRTCNominations> or scan the QR code:

