



### In This Issue

[President's Message...p1](#)

[2023 Conference Recap...p2](#)

[2024 Conference Update...p4](#)

[Nominations...p5](#)

[Legislative Update...p6](#)

[World Café...p8](#)

[Conference Highlights...p9](#)

## President's Message



**Wendy Strobel Gower**  
Yang Tan Institute on  
Employment and Disability,  
Cornell University

Wendy is the Project Director of the  
Northeast ADA Regional Center  
[www.northeastada.org](http://www.northeastada.org)

Hello NARRTC members! I hope you all had an enjoyable summer!

I'm actively working to readjust to students on campus. We have a great issue for you this time. Andre Washington, last years' VP and our current president elect, will provide an overview of this year's conference. Catherine Ipsen, our new VP and program committee chair, will share news about our 2024 conference that she and her program committee are working on.

Jae Kennedy, our legislative chair, has some interesting news about the work of the DRRC. Joann Starks will provide a run-down on open positions on the NARRTC Executive Committee for you to consider. Allen Heinemann, our research chair, will share a really interesting idea -- a Journal Club, and we have news of a research learning opportunity out of BBI. I bet you can't wait to dig in!

Before I let you go, I wanted to take a minute to congratulate a long-time NARRTC member, Jim Krause, on a prestigious award he received from South Carolina Gov. Henry McMaster. It is the Governor's Award for Excellence in Scientific Research. The [article announcing the award](#) speaks to Jim's long successful research career in community participation and health research for people with spinal cord injuries. Congratulations, Jim! We're proud to count you among our membership.

**Save the Date! May 21-22, 2024**

**Engaging the Community: Building Capacity Through NIDILRR Projects and Partnerships**

**2024 Annual Conference & Business Meeting**

Embassy Suites Alexandria Old Town, VA



## Webinar: Research Ethics for All September 20th, 2-3pm ET

The Institute on Disability (NH UCEDD) and Syracuse University are holding a webinar to introduce **Research Ethics for All**, an accessible research ethics education training for community research partners with developmental disabilities, on September 20, 2023 from 2 - 3 pm ET (**tomorrow**).

We hope that research teams inclusive of community research partners with developmental disabilities will be able to use **Research Ethics for All** as an alternative training to CITI training.

Webinar attendees will have the opportunity to learn:

- Rules and guidelines related to the education of community research partners
- How **Research Ethics for All** provides disability accessible education for community research partners involved in social and behavioral research
- Tips on using **Research Ethics for All** to build the capacity of your community research partners
- Strategies for receiving IRB approval to use Research Ethics for All with your community research partners

To learn more and register:

[iod.unh.edu/event/2023/09/learn-about-research-ethics-all](https://iod.unh.edu/event/2023/09/learn-about-research-ethics-all)

## 2023 Conference Recap

NARRTC 2023 Annual Conference was held on April 2023 at the Ritz Carlton Hotel, Pentagon City. A timely conference theme, **"More Than A Seat At The Table"** brought out the best of our profession.

The conference committee received 57 calls for proposal representations and 34 poster presentation submission. Submissions that focus on the future of disability-related research, policy and/or advocacy efforts in relation to the three domains of NIDILRR's research and development agenda: (1) Health and Function, (2) Employment, and (3) Community Living and Participation. Within these domains, papers were to focus on one or more areas: Community Participation; Diversity, Equity, and Inclusion; Education; Employment; Health; Knowledge Translation; Rehabilitation; and/or Technology. The conference planning committee had a tough time selecting presentations but felt a wide cadre of relevant topics were provided.

In all there were 37 plenary panels, and concurrent presentations, and 27 poster presentations, including many young investigators. (see photo highlights starting on p 9)

Conference registration was at its highest totals in recent years with 84 total registrations, including 9 student researchers. Long time NARRTC member and current President, Wendy Strobel Gower stated, **"In my opinion, this is the best NARRTC conference I've been involved in"**.

The much-anticipated plenary panel of the newly funded Equity Centers (RRTC on Community Living Equity Center at Brandeis University, RRTC on Equity in Health and Function for Adults with Physical, Cognitive, Sensory, and Developmental Disabilities for Marginalized Communities at the University of Michigan, and RRTC on Advancing Employment Equity for Multiply Marginalized People with Disabilities at Langston University) gave conference attendees the opportunity to hear an overview of each center's projects and the work ahead.

Continued on page 3

Conference recap from page 2

The NARRTC Knowledge Committee hosted the “World Café on Knowledge Translation” keynote session. One attendee mentioned regarding the World Café in their conference evaluation **“Loved this! My favorite part of the two days. It was great to have discussions and meet other grantees. The format and questions allowed for productive discussions while also learning and collaborating with others. More of this!!”** See p. 8 for a wrap-up of the event and plans for next year!

The hyper competitive “Best Paper” award was awarded to a team of authors, Jean Hall, Noelle Kurth, Catherine Ipsen, Andrew Myers and Kelsey Goddard. The paper titled: Comparing Measures Of Functional Difficulty With Self-Identified Disability: Implications For Health Policy (published in Health Affairs Vol. 41, No. 10). Dr. Jean Hall and Dr. Andrew Myers presented their paper during the conference. The competition for “Best Poster” was equally competitive, with more than 25 posters on display. The award was presented to Mariana Garcia Torres for Workplace Flexibility and ADA Title I: A Scoping Review. Photos from the poster session and awards are included at the end of this newsletter.

NARRTC was very pleased to present three Distinguished Service awards during the conference to Corey Moore, Michael Morris, and Senator Bob Casey, recognizing their impressive contributions to the field of disability through research, teaching, service, knowledge translation, or advocacy. We also presented Commendation Awards to Pimjai Sudsawad and Joe Caldwell, recognizing their contributions to advance knowledge translation and equity in disability and rehabilitation research.

Conference attendees were especially excited about the NIDILRR Technical Assistance (TA) Panel devoted to TA in areas of engaging multiply marginalized populations, data sharing and capturing outcomes. One attendee wrote **“open question/answer session was exceptional”**, another attendee simply stated **“more time.”**

One of the most awaited events of the conference is the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) Director’s presentation. Dr. Anjali Forber-Pratt delivered insightful updates for NIDILRR and ACL. Conference evaluation from one attendee stated **“Great balance of recapping info from the long term planning webinar, new updates, and Q&A.”** Another attendee comments **“Clear understanding of NIDILRR priorities and updates to bring back to my team and university.”**

NARRTC aspires to continue the NIDILRR Director’s address to the membership. We understand the importance of connecting with and having the opportunity to personally meet and ask questions that may affect research efforts of our membership. As the 2023 NARRTC Conference Chair, I would like to personally thank the conference committee, the NARRTC Executive Committee, the NARRTC membership, and NIDILRR leadership for assisting with making the conference and huge success. I encourage all our membership to save the date for the 2024 NARRTC Conference. Conference date is May 21-22, 2024. Embassy Suites Hotel, Alexandra Old Town is the host hotel. To register and make hotel reservation, visit NARRTC website at [narrtc.org/annual-meeting](http://narrtc.org/annual-meeting). Hope to see you there!

*Dr. Andre Washington, NARRTC President Elect.*

## 2024 Conference Update: Save the Date - May 21-22, 2024 Join Us in Old Town Alexandria!

The NARRTC conference planning for 2024 has commenced!

We have a date, a venue, and a theme. We are looking to our members to save the date and fully engage with this important opportunity for NIDILRR grantees. The conference dates are May 21-22, 2024 at the Embassy Suites, Alexandria Old Town, VA. Having the conference at the Embassy Suites will provide great networking opportunities for attendees at their complementary evening happy hours and breakfast buffets. NARRTC will also host lunch on both days, a session with NIDILRR staff, and a networking poster session with a cash bar on the evening of May 21st.

Our conference theme “**Engaging the community: Building capacity through NIDILRR projects and partnerships**” builds on NIDILRR’s Long-Range Plan and commitment to disability-led research initiatives. We want to hear how your projects have included disability voices and diverse groups to build capacity among advocates, programs, and policymakers. We want to know how your research dismantles ableism and builds equity for all. And, we are looking to connect mentors and mentees to combine forces and build the next generation of disability researchers.

Stay tuned for the call for conference proposals in October and additional collaboration opportunities as we build out the full agenda. If you want to get involved, have a great networking idea, or simply need something to pad your resume, please reach out to Catherine Ipsen, Conference Planning Chair at [Catherine.ipsen@mso.umt.edu](mailto:Catherine.ipsen@mso.umt.edu).

**Let’s build the 2024 NARRTC Conference together!**



### **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 [narrtc.org/how-to-join/narrtc-job-board/](https://narrtc.org/how-to-join/narrtc-job-board/) to learn more.

## Seeking Nominations for the NARRTC Executive Committee

The NARRTC Executive Committee invites the membership to consider nominating candidates for the election to be held at the 2024 NARRTC Annual Meeting on May 21, 2024, at the Embassy Suites - Alexandria Old Town. Member projects each have one vote per position, which can be cast by any project representative attending the conference.

We 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-PI, and early or mid-career project staff may even benefit more from this leadership experience. Members can expect light committee work for most of the year (a monthly one-hr. Zoom call), though there is a flurry of activity in the winter and spring to prepare for the annual conference. It's a great opportunity to get to know other experienced NIDILRR grantees and to see them as potential mentors and colleagues.

Positions open this year include:

- **Vice-President and Conference Program Chair** (1-year term, 2024-2025) This person should represent a NARRTC member project and be willing to lead a team of NARRTC colleagues to organize and conduct the next Annual Meeting of NARRTC (Spring 2025). The Program Chair VP has access to written materials on how to run the Annual Meeting as well as communication with past Program Chairs for advice and guidance.
- **Members-at-Large** (Two for 3-year terms, 2024-2027) These individuals should be representatives of NARRTC member projects and may be new to the organization, looking to become more involved, or of longer standing and who are looking to become re-involved. They participate in one-hour monthly calls with the Executive Committee and may participate with other NARRTC committees.

Learn more about these and other roles in the NARRTC By-Laws: [narrtc.org/sample-page/about/by-laws/#art6](https://narrtc.org/sample-page/about/by-laws/#art6)

You may self-nominate or nominate a colleague who will agree to serve if elected. If you have questions, please contact Nominating Committee Chair, past-president Jae Kennedy [jjkennedy@wsu.edu](mailto:jjkennedy@wsu.edu). Watch for the Call for Nominations that will be sent out in a few months by the Nominating Committee.





## Legislative Committee Update



Jae Kennedy, PhD  
Chair, Nominating &  
Legislative Committees

In July 2023, Dr. Bonnie Swenor, and I published a commentary in the Disability and Health Journal titled "It's Time for the NIH to Formally Designate People with Disabilities as a US Health Disparity Population" (PMID: [37069003](#)).

The Minority Health and Health Disparities Research and Education Act of 2000 (P L. 106-525), authorizes the Director of NIMHD to make this designation. But on Friday, September 1, 2023, his advisory board rejected the arguments made in our commentary and related arguments by dozens of disability advocacy groups, including NARRTC, the Coalition of Citizens with Disabilities, and the Disability and Rehabilitation Research Coalition.

After stewing over this decision during the long Labor Day weekend, Bonnie and I drafted a letter to DHHS Secretary Xavier Becerra, stating:

We are writing to express our strong reservations about the recent (September 1, 2023) recommendation of the National Institute of Minority Health and Health Disparities (NIMHD) Advisory Committee to not designate people with disabilities as a "health disparity population." This inaction is not consistent with the Administration's commitment to people with disabilities; disrupts current NIH Diversity, Equity, Inclusion, and Accessibility (DEIA) efforts; fails to consider current models and theories of disability; and does not include the perspectives of people with disabilities.

Specifically, we assert that:

- All required criteria have been met for the director of the NIMHD to designate people with disabilities as a health disparity population.

- The NIMHD Advisory Committee's recommendation undermines current NIH DEIA initiatives and contradicts the Biden administration's equity efforts.
- The NIMHD Advisory Committee's stated reasons for not designating people with disabilities as a health disparity population are based on ableist assumptions and a biased view of disability.
- The NIMHD Advisory Committee did not include anyone with a disability, which is deeply problematic.

Bonnie also reached out to the Partnership to Improve Patient Care (PIPC), chaired by disability advocate and ADA OG, former Congressman Tony Coelho (D-CA, 15th District), who advised them to complete a sign-on campaign by Friday, September 8, as Congress was returning after its summer recess and celebrating the 50th anniversary of the Rehabilitation Act.

We scrambled to send out the letter to disability researchers and healthcare providers, including the full NARRTC membership, with a ridiculously short timeline for signatures. By Friday, we had gathered 1,291 signatures. Former Congressman Coelho sent our letter, along with a companion letter drafted by the PIPC, to Secretary Becerra at 5 p.m., September 8, noting:

While we are very disappointed in the decision made by the NIMHD Advisory Committee, we also recognize that the recommendation not to include people with disabilities as a health disparity population is just that - a recommendation. We know from prior experience that you have worked diligently to advance issues important to the disability community. Therefore, we also urge you to advance a swift course correction on this issue and move to designate people with disabilities as a health disparity population.

Continued from page 6

Recently, NIMHD director Elisio Perez-Stable wrote a boilerplate response, concluding with:

"I sincerely thank the people with disabilities who shared their experiences along with the invited scientists, leaders, individuals, and groups with expertise in disability issues and health disparities research who provided their input to the working group and continue to provide their input to me, Acting NIH Director Tabak, and Secretary Becerra. I look forward to receiving the final report from the NACMHD in the upcoming weeks and will announce a final decision thereafter."

We're considering sending a follow-up letter asking the NACMHD to address the specific concerns raised in our previous letter - evidence of health disparities, consistency with other DHHS and NIH DEI initiatives, inaccurate characterizations of disability research and operational definitions, and failure to include people with declared disabilities in the deliberation process.

In the meantime, the NARRTC legislative committee will be drafting a comment on a proposed change to the NIH mission statement (see Your paragraph text for more details). NIH's current mission statement is "to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability." The proposed revision, drafted by Lisa lezzoni and co., is "to seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health and prevent or reduce illness for all people." I think this is much more inclusive, but we'll be hashing out the details in October.

## From the Communications Committee

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

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

Upcoming issues may include

- Conference preview
- 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](mailto:modum@heitechservices.com)



## Join the Journal Club!

NARRTC's Research Committee is seeking members' feedback on developing a quarterly journal club. Participants will nominate articles for discussion and focus on the methodological and measurement issues, and how they influence findings and conclusions. If interested, please contact Allen Heinemann at [a-heinemann@northwestern.edu](mailto:a-heinemann@northwestern.edu).

## A Knowledge Translation (KT) World Café

The 2023 annual meeting kicked off with a lively “world café” focused on innovative KT approaches and practices. Participants enjoyed coffee while seated at tables covered in butcher block paper with crayons and floral arrangements available to encourage creativity. During the hourlong event, participants were able to join up to three small group discussions distributed across nine tables.

Table moderators took notes, which are summarized below. Much appreciation to the KT Committee members who contributed: Troy Balthazor, Cindy Cai, Marsha Ellison, Marianne Farkas, Mark Harniss, Kathleen Murphy, Krys Standley, and Michelle Zorilla as well as Felice Trirogoff and Joann Starks from the Center on Knowledge Translation for Disability and Rehabilitation Research. Stay tuned for news about NARRTC 2024’s repeat café!

*What are new products and practices to identify and reach your audiences?*

Methods identified encompassed using digital tools like questionnaires on platforms like Qualtrics, podcasts, live “Ask Me Anything” sessions on Zoom, email marketing with tools like ConstantContact and Mailchimp, and social media management tools such as Loomly and HootSuite. Some participants mentioned the use of artificial intelligence (AI) tools like ChatGPT for creative content generation, involving parents and peers in content creation, and exploring platforms like TikTok and Reddit for audience-specific outreach. The participants underscored the importance of adapting to evolving communication platforms, maintaining ethical standards, and actively involving the target audience in content creation to effectively reach and engage them.

*What are best ways to engage in KT with groups underserved by your project?*

Participants noted the need for not only for diverse representation but also recognizing the diversity within underserved groups. They recommended involving youth and social media experts in KT efforts and underscored the importance of building trust and relationships within communities. These efforts require allocating resources for outreach, forming partnerships with grassroots organizations, and committing to engagement beyond initial project timelines.

*What are ways of generating engagement-both with external audiences and your own team?*

A third discussion theme was how to generate project staff and external partner engagement in KT efforts. Participants noted the importance of managing project staff energy levels, fostering their skill development, and aligning KT efforts with individual staff career goals. Consider making KT projects entertaining for both the project team and the audience, such as in use of videos or infographics. With respect to external partners, participants emphasized the importance of early involvement of potential project findings in research design, as well as for establishing communication teams for bidirectional communication, and showcasing impact to funders. Rather than selecting only one method, participants noted that the strategies can work together to reinforce the commitment of both the internal team and project impact.





## 2023 Conference Highlights



Anjali Forber-Pratt, PhD, NIDILRR's Director, shared updates on NIDILRR's Long Range Plan and other upcoming activities. Kolton, her service dog, is seated below.



The NIDILRR TA Panel offered members an opportunity to ask about the award process, open research requirements, and much more. (l-r Pimjai Sudsawad, Phil Beatty, Shelley Reeves, Dr. Forber-Pratt, and Kolton)



Best Poster award went to Mariana Garcia Torres for Workplace Flexibility and ADA Title I: A Scoping Review, presented by Rayna Sage



Best Paper award presented to Jean Hall, Noelle Kurth, Catherine Ipsen, Andrew Myers, Kelsey Goddard, presented by Sarah Parker Harris



Best Paper finalist presented to Michelle Zorilla, presented by Sarah Parker-Harris



Corey Moore received the Distinguished Service Award, presented by Edward Manyibe and Robin Jones



Michael Morris received the Distinguished Service Award, presented by Barry Whaley and Robin Jones



Pimjai Sudsawad received the Commendation Award, presented by Kathleen Murphy and Robin Jones

## Meeting the Equity Centers



Kim The, Teresa Nguyen, and Jennifer Lee-Rambharose, from the Community Living Equity Center



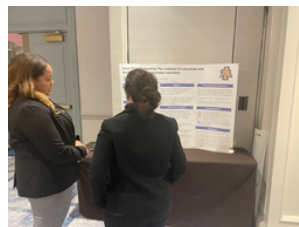
Shakira Cohen and Andre Washington from the RRTC on Advancing Employment Equity for Multiply Marginalized People with Disabilities (LU2E-RRTC).

## Poster Session Success!

We were so excited to welcome more than 25 posters for the 2023 conference, including many from young investigators! Here are just a few of the contenders for Best Poster.



Kierra Carter from the Langston RRTC



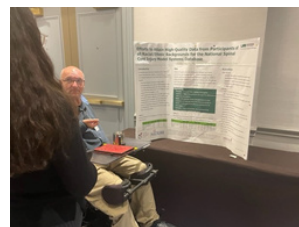
Shakira Cohen from the Langston RRTC



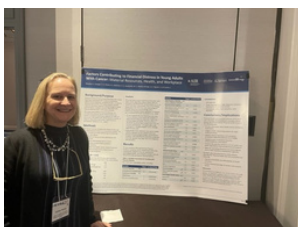
Yazmin Castruita-Rios from the Transitions ACR



Sandy Magaña and Mariana Garcia Torres review the PODER poster



Phil Klebine from the National SCI Statistical Center



Kathleen Murphy from the Center on KT for Disability and Rehabilitation Research

Mark Harniss from the ADA Knowledge Translation Center

