

Jacqueline (Jackie) McGinley**Associate Professor, MSW Program Director**

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Background

Jackie McGinley is a licensed social worker and Assistant Professor in the Department of Social Work. She earned her MSW (2007) from the Rutgers University, School of Social Work and her PhD (2018) from the University at Buffalo, School of Social Work. She also completed a year-long fellowship with the University of Rochester, receiving advanced research and clinical training from the Leadership Education in Neurodevelopmental Disabilities (LEND) program. Prior to joining the Binghamton University faculty, she had four years of experience as a social work educator having taught at both the undergraduate and graduate levels, online and in seated courses, and across topic areas.

Her current program of research grew out of over 20 years of experience in the field of disability. During this time, she was privileged to support seriously ill clients during some of their most vulnerable moments, witnessing the emergence of a new and urgent issue: aging and end-of-life care for people with intellectual and developmental disabilities (IDD). She pairs these profound practice experiences with her acumen as a qualitative researcher to pursue an impactful and dynamic research agenda. Her mission as a social work scholar is to lead translational research that improves care for people with disabilities as they age, experience serious illness, and reach life's end.

Education

- PhD, University at Buffalo
- MSW, Rutgers University
- BA, Elmira College

Research Interests

- Intellectual and Developmental Disabilities
- Aging Populations and their Families
- End-of-life Care and Bereavement

Dr. Marissa Andréah Diaz is a Postdoctoral Research Associate with the Department of Disability and Human Development at the College of Applied Health Sciences at the University of Illinois Chicago. Her research primarily focuses on on health equity for people with intellectual and developmental disabilities, specifically at end of life. Her PhD at the University of Lucerne was funded by Disability Advocacy Research in Europe (DARE), funded by the European Union's Marie Skłodowska-Curie Actions program. She was previously a Postdoctoral Research Associate at Washington State University's Department of Community and Behavioral Health as a fellow with The Collaborative on Health Reform and Independent Living (CHRIL).

Today

Eric Berg, NACDD 3:28 PM

I'm sorry, are we letting people in now?

Messages addressed to "meeting group chat" will also appear in the meeting group chat in Team Chat

You to Waiting room participants 3:29 PM

We will open up the room in one minute

Due to the large number of participants in this meeting, system messages for those who joined or left have been disabled

Jackie McGinley 3:30 PM

Also, I am from New Jersey and practiced there for a few years. So nice to see NJ represented!

JJ_NACDD_ReadAI 3:31 PM

Jill and Stephanie added JJ_NACDD_ReadAI to the meeting.

Read provides AI generated meeting summaries to make meetings more effective and efficient. View our Privacy Policy at <https://www.read.ai/pp>

Type "read stop" to disable, or "opt out" to delete meeting data.

Kim Mercer-Schleider 3:32 PM

Kim Mercer-Schleider, DD Council IL

Jennifer Goldman, NYS CDD 3:32 PM

Jennifer Goldman, NY CoP lead

Chris Reeve 3:32 PM

Chris Reeve, Florida, Program Director for our BADN projects

Brooke Lovelace-Iowa DD Council 3:32 PM

Brooke Lovelace Iowa

Yumi Shirai 3:32 PM

Yumi Shirai from Arizona, I am co-leading our health equity team in our state.

Allyson McCain 3:32 PM

Allyson McCain, Kansas DD Council

Jill Jacobs 3:32 PM

Jill Jacobs. NACDD Executive Director

You 3:32 PM

Hi Everyone and welcome to today's BADN National CoP TA Session! Please include your name, state and role with the Bridging Aging and Disability Networks Initiative.

Darryle Powell 3:32 PM

Hello. Darryle Powell-Alabama DD Council

Julie Bergeson, IHHS 3:32 PM

Julie Bergeson, Iowa Co-Lead

Walt Glomb - CT Council on DD 3:32 PM

Walter Glomb

Executive Director

Connecticut Council on Developmental Disabilities

kimberly.berg 3:32 PM

Kimberly Berg, NY Council

Mercedes Witowsky, NJCDD 3:33 PM

Mercedes Witowsky New Jersey Council on Developmental Disability Co-Lead

patricia brennan-NJ DDD 3:33 PM

Tricia Brennan, NJ Division of Developmental Disabilities-Director, Office of Education on Self-Directed Services, Priority Waiting List, and Special Projects.

Alison Giannini, DDS (she/her) 3:33 PM

Good afternoon! My name is Alison Giannini, from the California Department of Developmental Services, and serve as co-lead for the grant alongside our partners at the California Department of Aging

DDC-Amelia Kyewich-Kaneholani 3:33 PM

Amelia Kyewich-Kaneholani, Hawaii DD Council

Tanya Bautista, CDA 3:33 PM

Tanya Bautista, California, aging co-lead

Kelly Hsieh 3:33 PM

Kelly Hsieh, UIC TA/Evaluation team for BADN

Joe Caldwell 3:33 PM

Joe Caldwell, Brandeis University, TA Partner

Daintry Bartoldus 3:33 PM

Daintry Bartoldus

Executive Administrator

Hawaii State Council on Developmental Disabilities

Tani Salazar (she/her) EOA ADRD Svcs Coordinator 3:33 PM

Coffee! ☕

Tani - from Hawai'i Executive Office on Aging. I'm here supporting our awesome Hawai'i DD Council who is the lead. 🙌

Andrea Mancini, NJ Division of Aging Services 3:33 PM

Andrea Mancini, NJ Division of Aging Services

Pamela Stafford 3:34 PM

Pamela Stafford NM DDC

Marissa Diaz 3:34 PM

Marissa Diaz, Postdoctoral Researcher from University of Illinois Chicago

Abby Schindler 3:39 PM

Abby Schindler, University of Illinois Chicago Institute on Disability and Human Development

Caitlin Crabb 3:42 PM

Caitlin Crabb, Illinois UCEDD.

You 3:57 PM

Please share any exemplary programs in your state or examples of disseminating information on these models to other organizations?

Start thinking about your questions for Dr. McGinley and Dr. Diaz. You can either include them in the chat, use the Q&A feature at the bottom of your screen, or simply raise your hand when we open it up to questions after Dr. Diaz's presentation.

Mellie Adu, AZSILC (she/they) 3:58 PM

This was so fabulous. Unfortunately, I only had 30 minutes to connect today, and I am so glad that I did. Thanks so much for prioritizing this important component of people's lives and our work. - Mellie Adu, Arizona BADN CoP

Walt Glomb - CT Council on DD 4:04 PM

On 10/17/23, Wayne Seidel, Director of Case Management at our State of Department of Developmental Services, described their End of Life Planning Resource to our BADN CoP. I would be happy to connect Wayne to others who are working on this topic.

Joe Caldwell 4:21 PM

Really excellent presentations!

Jackie McGinley 4:21 PM

@Marissa Diaz - Phenomenal presentation and project, Dr. Diaz!

Kelly Hsieh 4:23 PM

Both presenters are fabulous—thank you so much!

You 4:24 PM

I am struggling seeing all of the participants, so if you have a question or your hand raised, please feel free to jump in!

Walt Glomb - CT Council on DD 4:25 PM

I will share this webinar with our DDS and AAA folks, and I expect that they will wish to connect with the speakers off line. Thank you.

Joe Caldwell 4:27 PM

We do a lot of work with National Core Indicators (NCI). I could be wrong, but don't think there are any questions in the survey about end of life planning right now. That might be a good area for future question development. Also, states can add their own state questions.

You 4:34 PM

Allyson, can you please share the surveys you created/used with both people with lived experience and family caregivers?

Alison Giannini, DDS (she/her) 4:36 PM

It was an amazing webinar!

You 4:37 PM

Excellent job on the webinar on palliative/hospice care Allyson -- for those of us that missed it, I'm so glad we have a chance to view the recording!

Mary Willard (NACDD) 4:30 PM

I just am having a hard time formulating my question- I am always curious what do you think are the most important lessons you have learned in your research that could be useful for those in the applied fields working with families and individuals on these sensitive topics?

Allyson McCain 4:39 PM

Here is the webinar recording and slides: <https://www.kcdd.org/hospice-and-palliative-care-webinar>

Walt Glomb - CT Council on DD 4:37 PM

Before an individual experiences their own end of life, they will probably experience the loss of their parent-guardian-caregiver. How do I talk to my son, who lives with Down syndrome, about my own inevitable death? Especially now in the era of self-directed care, where there is no agency (read institution) managing services and supports, how does the

individual transition to a new circle of support?

Marissa Diaz 4:41 PM

Strictly talking about how to begin the conversation, The Victoria & Stuart Project has great (free!) Easy Read resources to begin conversation about end of life issues, like funerals. I will say that these materials are UK-specific, so some guidance may not be fully applicable

Marissa Diaz 4:41 PM

<https://www.victoriaandstuart.com/end-of-life-care-planning-toolkit>

Walt Glomb - CT Council on DD 4:41 PM

TY

Jackie McGinley 4:45 PM

Updating these as a great resource. The Talking End of Life resources Serena mentioned also has materials about the aging, serious illness, and/or death of others (not just self): <https://www.caresearch.com.au/tel/Modules>

Kyoko Coco, NJCDD 4:46 PM

[Go Wish – Coda Alliance](#)

Jackie McGinley 4:43 PM

@Allyson McCain - Thank you for your phenomenal work ... I particularly appreciated your insights about the complexities relative to state policies that impact decision-making and care at end-of-life! I cannot wait to watch the webinar. You mentioned a resource (I might have missed the title), "Understanding Hospice and Palliative Care"? Is that something that is available publicly? I have been trying so hard save links to resources and files in the hopes of centralizing information.

Allyson McCain 4:48 PM

Thank you! I learned so much from your presentation – thank you for all of the work you are doing. Yes, here is the plain language tool we created for individuals with IDD and there families:

<https://static1.squarespace.com/static/668eca9c8d28c632ecdf753c/t/67f98050121d3927354fe406/1744404573113/Hospice+and+Palliative+Care+PLG+2pages.pdf>

Jackie McGinley 4:49 PM

Amazing, thank you!

Alison Giannini, DDS (she/her) 4:51 PM

[Thinking-Ahead-2022-Web.pdf](#)

Alison Giannini, DDS (she/her) 4:51 PM

[Home](#) - Link to coalition website

[People With Developmental Disabilities Resources](#)

if you navigate to the resources menu from the home page of the coalition, you can navigate to the above link I just posted

Alison Giannini, DDS (she/her) 4:58 PM

Thank you, Mechelle! ❤️

Alison Whyte - DC DD Council 4:59 PM

DC uses the Thinking Ahead guide in the person centered planning process

Alison Whyte - DC DD Council 4:59 PM

It's so helpful!

You 4:59 PM

Please take a few moments to complete our evaluation for today's

webinar: •https://uic.ca1.qualtrics.com/jfe/form/SV_1QPMnCXJzCkNznM

patricia brennan-NJ DDD 5:00 PM

Thank you everyone!

Ruth 4:59 PM

Michelle, I love the workbook. How can I receive a copy? I am a caregiver for my adult Down Syndrome son. He is 55 years old.

Alison Giannini, DDS (she/her) 5:00 PM

Hi Ruth, if you visit this site you should be able to access a copy [People With Developmental Disabilities Resources](#)

if you run into any issues let me know, happy to help

Sandra Markwood 5:01 PM

Great Session!!!! Thank you!!

Chris Reeve 5:01 PM

Thank you everyone! It was excellent

Kyoko Coco, NJCDD 5:01 PM

I learned a lot. Thank you!

Alison Giannini, DDS (she/her) 5:01 PM

Great meeting, thank you all! I have a 2 pm I need to hop to :)

Jackie McGinley 5:01 PM

Thank you for the privilege of being in this space with you all.

Poki'i Balaz 5:01 PM



Marissa Diaz 5:01 PM

Thank you!