



# Lived Experience Leading the Way

*Catchy subtitle here*

July 25, 2024

NCIL Annual Conference

United  
Healthcare



**UnitedHealthcare**  
**National Advisory Board**

# National Advisory Board

- In 2012, UnitedHealthcare Community and State formed an advisory board to serve as an independent advisory council to provide input in actively engaging members, providers, advocacy groups, and other key stakeholders in the design and delivery system that supports individuals with special health care needs.
- The National Advisory Board makes recommendations, develops and champions innovations, and advises on member engagement strategies that support clinical approaches.
- The goals of the National Advisory Board are to:
  - Cultivate a consumer-centered culture
  - Advance awareness and knowledge of individuals served
  - Identify emerging trends or policy issues
  - Create a pathway to enable policy advancements
  - Develop and recommend innovations for populations with special health care needs





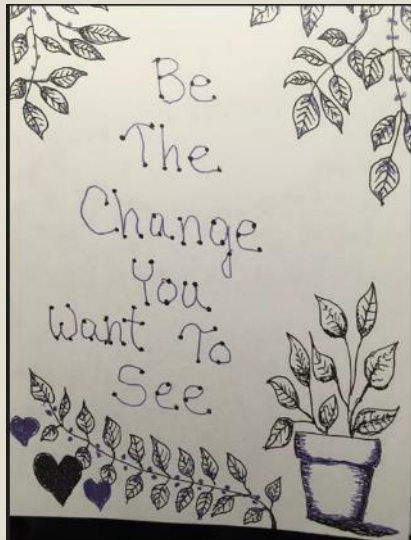
# **Journey as a Self-Advocate and Impact of NAB**

# My Journey to Becoming a Disability Advocate

by Jennifer Kucera



Miley



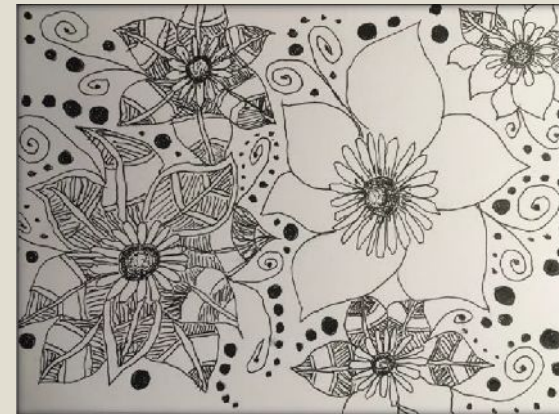
- Reason for my advocacy success is due to United Healthcare's inspiration
- Helped find public voice
- Exposed to different avenues to tell "my story" and build knowledge base
- Validating my experiences
- Sponsorships (conferences)

## How My Disability Systems Advocacy Began

- 2018. Meeting of Melvin Harris, Heather Cianfrocco, and Steve Nelson in Dublin Oh
  - United Health Care of Ohio's Open House Guest Speaker
  - Math Instructor at Elevate K-12
  - State ID, Ohio Opportunities for Ohioans with Disabilities (OOD) introduction
  - Amy Swanson's recommendation to the National Advisory Board
- Aug 2019 NAB Phone interview with Catherine Anderson
- Nov 2019 first NAB Meeting
- 2019 turned 50. Life turned into dream, Advocacy full time
- 2019: Member Perspective Video - Online
  - Credibility and Validation, LinkedIn page, networking



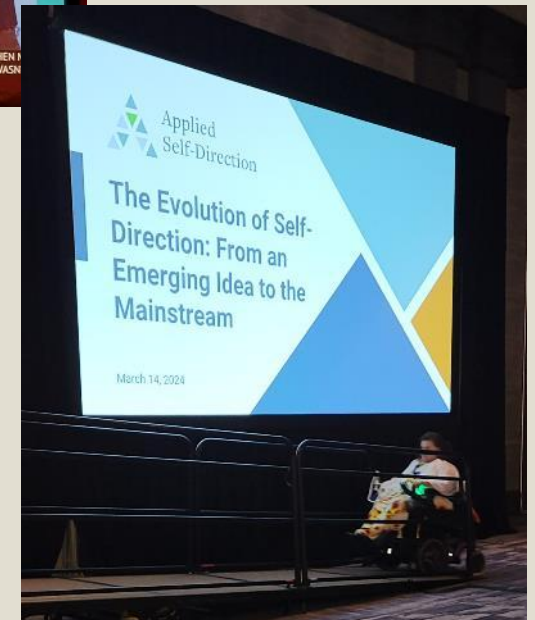
Heather Cianfrocco & Jen Kucera



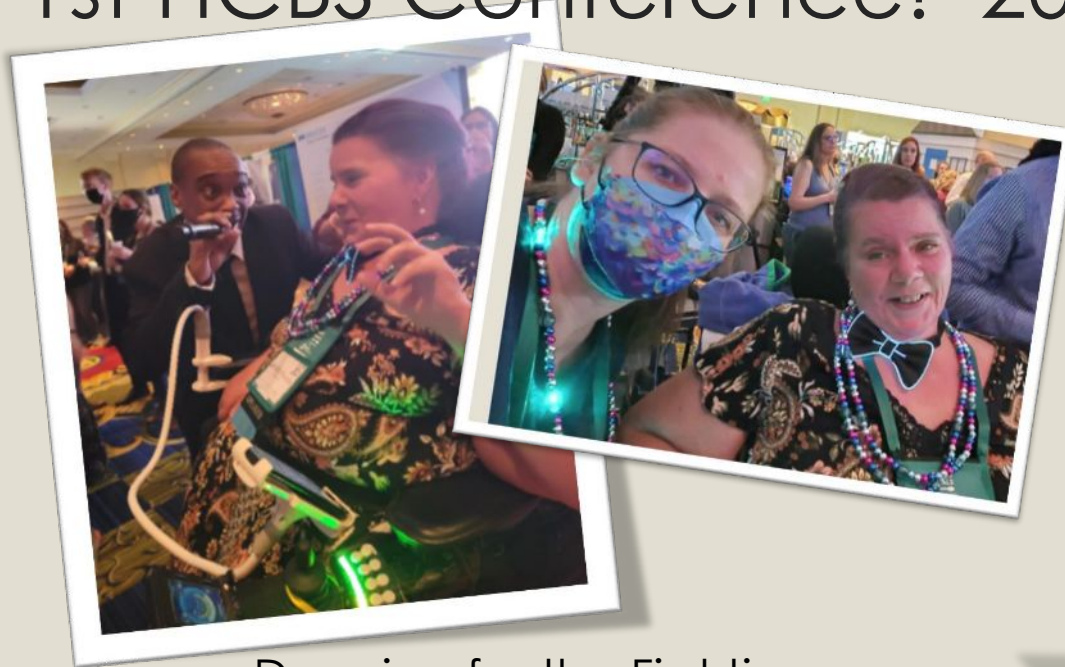
# Beginning of all Conferences

## National Advocacy

- MHPA opening session with Catherine Anderson, 2021
  - Speaking at MHPA was amazing experience
- HCBS Conference and dancing for 1st time, 2021
- Independent Living discussion, 4/2/21 Ohio UHC meeting
- Disability Policy Seminar, 2022
- National Council of Independent Living, NCIL Conference, 2022
- HCBS Conference, 2022
- Community Health Institute Conference, Chicago, 2022
- NAB Quarterly Meetings, 2019 – Present
- Caring Across Generations fellowship, 2022
- Advancing States Adaptive Fashion Show, 2023
- Advancing States ARPA Summit, 2023
- NACDD Conference presenter 2023, Self-Direction
- Self Direction Conference presenter, 2024
- IEC work, beginning in 2023
- NCOA Direct Care Workforce Strategies Center, DCW Advisory Committee, 2023



# 1st HCBS Conference! 2021



Dancing for the First time



2<sup>nd</sup> HCBS Conference 2022



# Current State Advocacy

## Today's advocacy:

- Ohio Olmstead Task Force, 2022
  - Chair of the Taskforce
    - Celebrate Our Carers Event – Ohio Statehouse
    - Legislative Day – Ohio Statehouse
  - Legislative Committee, DCW workgroup
  - Steering Committee
  - Housing Advocacy Workgroup
- Co-Host for Breaking Silences Advocacy Group
  - MyCare-Ohio Waiver Committee
  - Self-Direction Committee
- DD Council Chair, November 2023
  - Public Policy Committee
- Ohio Department of Health (ODH) Emergency Preparedness Planning for PWD, Apr 2022



**Focus on Self-Direction, MyCare and Direct Care Crisis!**

# Artwork



- Showing of “Love”, Toledo Art Museum 2022



Disabled Women Make History (And Art) Featured Artists

Jacelyn Roy	Alicia M Hopkins
Marie Dagenais-Lewis	Alana Henning
Claire Moore	Jennifer Kucera
Laura Mason	Suzanne Brock
Ranee Wood	Jennine Marie Dallen
Shelby Rios	Kathy Hanneman
Ashtin J Wolford	Haley Gardner
Megan Braun	Jenna Frabig-Sanchez
Katie L Watson	

A colorful artwork featuring the word "LOVE" in large, stylized letters. The letters are filled with various patterns and colors: 'L' is orange and yellow, 'O' is blue and white, 'V' is purple and white, and 'E' is pink and white. The background is green with yellow leaves and small flowers. The artwork is set within a white frame.

The background of the slide is a vertical wood grain texture, showing various patterns and knots in shades of brown and tan. The texture is consistent across the top and bottom sections of the slide.


Edward Mitchell

FPPT.com



# Edward Mitchell








**HELP SOLVE THIS CRIME**  
**Victim of a Hit-n-Run Driver**  
**March 2003 - Ashport Road**  
If you have information about this case please call  
 Madison County Sheriff's Office  
 731-423-6000  
 or  
 Crimestoppers at 424-tips


**\$5000 REWARD \* \$5000 REWARD \* \$5000 REWARD \* \$5000 REWARD**

Officials believe the vehicle that struck Edward Mitchell was an older-model dark vehicle, similar to a Jeep Wrangler, or Jeep truck with larger than normal-size tires.

My hit-and-run accident took place on Ashport Road, near Blankenship Used Car & Autobody, which is down the street from Pope Elementary School, and Pleasant Plains Road. Here is a map of Ashport Road, including Google Earth pictures of the area.





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TN Council on Developmental Disabilities

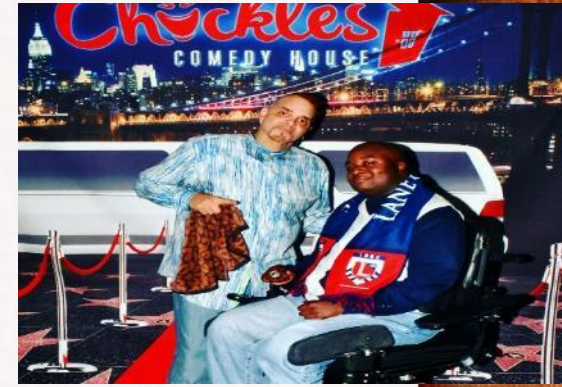
**#DisabilityMeans** 

finding a place to **belong & excel.**






# Who is Edward?



# Why the work of the NAB is important.



**YOU CAN \$AVE.  
YOU CAN DREAM.**

YOU CAN ACHIEVE A BETTER LIFE EXPERIENCE WITH AN ABLE ACCOUNT.

**JOIN US AND INVITE OTHERS WHO MIGHT BENEFIT FROM AN ABLE ACCOUNT FOR #ABLEtoSave MONTH THIS AUGUST!** Each week we will be sharing our ABLE success stories and ABLE tools and strategies with you. We look forward to having you join us!

**Stay tuned for more information about #ABLEtoSave Month and ways to get involved.**

*"Because of my ABLE account, I will have a better and more financially secure future."*  
— MRS. ABLE ACCOUNT OWNER

**DISABILITY ACCESS & INCLUSION  
IN AFRICAN AMERICAN  
COMMUNITIES**

Wednesday, October 26, 2021 | 7:00 PM EDT

**MODERATOR**

Bill Gould  
Director of Equity & Inclusion  
National Disability Institute

**PANELIST**

Bro. Edward Mitchell  
ABLE Advisor  
ABLE National Resource Center

Bro. Darrell Rice  
Chief Executive Officer  
Embrace, Elevate

Bro. Gerald Johnson II  
Chief Development Officer  
Alpha Phi Alpha Fraternity, Inc.

f y WATCH ON ALPHA PHI ALPHA FACEBOOK AND SPHINX TV

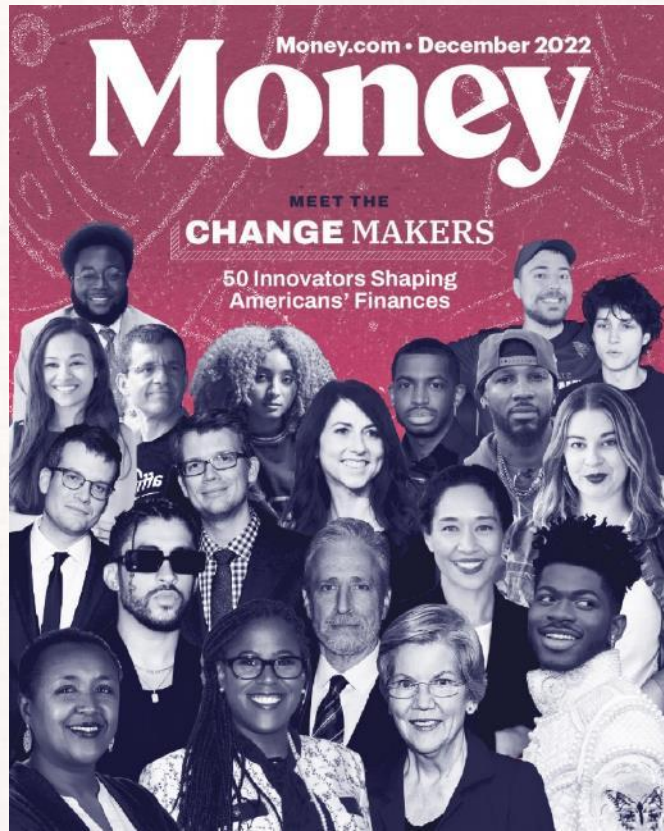
What gets me out of bed in the morning.



**"Supporting Economic Stability and Self-Sufficiency as Americans with Disabilities and their Families Age"**



# Ways to improve access to and opportunity for self-direction.







**Theo W. Braddy**  
**Executive Director**  
**National Council on**  
**Independent Living**

# Theo W. Braddy

- Theo W. Braddy has advocated on behalf of people with disabilities for over 40 years.
  - At the age of 15, he became a person with a disability due to a high school football accident that left him paralyzed from the neck down.
  - In 1988 he was hired as CEO of the Center for Independent Living of Central PA, where he served for over 30 years.
  - As CEO, he created a CIL that became a strong and growing voice for people with disabilities, and started the Living Well with a Disability Initiative.



# National Disability Advocacy

- He currently serves as Executive Director of the National Council on Independent Living (NCIL).
- He has received appointments from Governors, recognition from U.S. Senators and state and federal policymakers as a disability advocate and leader.
- In 2023 he joined the UHC National Advisory Board.





# **National Advisory Board Work to Date**

# Partnership with Association of Clinicians for the Underserved

## Caregiver Webinar Series



### Facilitated Lunch & Learns for Providers

Content developed with NAB feedback.

- Understanding Caregiver Roles, Responsibilities and the Workforce Landscape
- Caregivers as a Window into the Living Environment



### Trainings for all clinic staff

Featuring clinical subject matter experts and individuals with lived experience.

- Equity, Unconscious Bias, and Other Critical Considerations When Working with Healthcare Consumers and Their Caregivers
- Caregivers as an Ally for Emotional Support



### Other resources that can support clinics

- Getting the Conversation Started: Engaging Consumers and their Caregivers and the Legal and Ethical Implications
- Communication and Conflict Resolution for Working With Caregivers and Consumers



# Championing Self-Advocacy

Celebrating  
Self-advocacy  
during Disability  
Pride Month

Empowered to  
speak up: the  
value of childhood  
self-advocacy

Self-Advocacy in  
Adulthood

Self-Advocacy in  
Older Adulthood

Recognizing  
Developmental  
Disability  
Awareness Month

Videos and blogs  
released  
throughout 2023 –  
2024



## UnitedHealthcare Disability Taxonomy

- Goal: Develop data structures to facilitate identifying populations that experience disparate health outcomes to inform interventions to improve the quality of care those populations receive.
  - Information not used in benefit decisions
  - Prioritized information directly from the individual
  - Collected information needed to serve the person
- Implementing a disability methodology allows additional outreach to individuals most likely living with a disability to be deployed and enables investigation into:
  - How best they can be assisted on their health journey.
  - Disparities and inform interventions to alleviate those disparities.

## Supporting Caregivers

- Partnership to develop a curriculum to provide training to new caregivers of people who self-direct
- Curriculum development on track to be completed by the end of 2024

## Additional National Advisory Initiatives

- Addressing Elder Abuse
- Culture of Access
- Maximizing Stakeholder Engagement



# Continuing Efforts



## National Strategy on Self-Direction for UHC

- Providing guidance on the development of policy papers and research.
- Assisting in the execution of market-level summits with stakeholders and state policy leaders.
- Guiding UHC's review of operational practices to increase utilization of self-direction.



## Providing Ongoing Strategic Direction to UHC

- Staff continuing education courses on disability.
- Guiding new partnerships with disability stakeholders.
- Operational policy review and updates in response to feedback from board.







# **National Advisory Board Impact on Members**



## Board member engagement at Conferences

Board members have presented about their work to influence UHC at national and local conferences, highlighting the power of advocacy with Medicaid health plans.

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## Advocacy Leadership

Future and emerging leaders have connected through the work of the Advisory Board, growing the pipeline of disability advocates engaged with UHC.

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## Best Practice in Medicaid

UHC is a leader in Medicaid Managed Care and having disability leaders advising plans that serve them is a best practice that should be replicated. *“Nothing About Us without Us!”*

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## Personal Impact to Board Members

Involvement with NAB has impacted individual advocacy.



# **Applying Advocacy Lessons Locally**

# Shaping Medicaid Managed Care through Advocacy

- Medicaid Managed Care plans that cover LTSS must have Member Advisory Committees (MAC)
- D-SNPs must also have Enrollee Advisory Committees
- MACs are a key stakeholder engagement strategy for gaining meaningful member perspective, identifying opportunities to improve, and reporting action steps from their previous insights
  - Members of Medicaid Plans can advocate for change through MAC engagement
  - People with lived experience have an important perspective that must be heard and prioritized on MACs
- MACs are just one format to collect member insights.
  - Plans may also have provider advisory committees, stakeholder engagement committees or community advisory committees that target and engage key voices that can inform, influence and shape plan decisions.
  - Plans will also conduct member surveys and other tactics to gather member input.
- State Medicaid Agencies must also have MACs





# Discussion