



July 22-26, 2024

# A World of Opportunities

## 2024 NACDD Annual Conference

Capital Hilton, Washington DC & Virtual

Thank you to our sponsors!





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# Letter from the Executive Director & Board President

Hello Everyone,

Welcome to the 2024 National Association of Councils on Developmental Disabilities (NACDD) conference! We are happy to have you here. This conference is a time for us to share our knowledge, learn from each other, and work towards making life better for people with developmental disabilities.

This year's theme is "A World of Opportunities." This theme underscores our commitment to include everyone and empower people with disabilities. Over the next few days, you will attend workshops, panels, and speeches by top self-advocates and other experts. We have worked hard to offer sessions filled with useful information, practical tips, and fresh ideas.

The annual NACDD conference is THE place to build advocacy networks. We want you to connect with old friends and meet new people. Conference sessions are not the only place to do that. The best relationships often start through casual gatherings. Wednesday's State and Territories Showcase is a great example of one such opportunity! We hope you take advantage of this new and exciting event!

A special thank you to our staff and sponsors for making this event possible. Please take a moment to stop and thank the NACDD staff. Their hard work ensures a great experience for all of us. Our sponsors help NACDD explore new ideas to help people with developmental disabilities live their best lives. Please take some time to learn more about them. You can find more information about our sponsors on the conference platform.

To the NACDD Board of Directors, conference committees, and the DD Councils across the country: Your guidance and support are truly appreciated. We could not do it without you.

And, most importantly, thank you to YOU, the conference attendees. We recognize that you are making time in your busy lives to come to Washington DC to be with us. We are confident that NACDD 2024 will open a World of Opportunities for you and your Council. Together, let's learn, motivate one another, and build connections that will create lasting change.

Looking forward to fun and productive days ahead.

Warm regards,

Jill Jacobs

Kirsten Murphy

# Conference Information

## Need Information or Assistance?

The NACDD staff will be wearing staff ribbons on their name badges. Please come to the Registration Desk if you need assistance.

## Is there WIFI?

Yes, WIFI will be made available to all participants in the meeting areas starting Monday morning. The passcode is (NACDD2024)

## Is there a business center where I can print?

The business center is in the lobby area. NACDD staff will have a printer as well.

## Does NACDD have a lost and found?

All items lost during the conference should be gathered at the registration desk until the end of the conference (3:00 pm Thursday July 25th) and will then be transferred to the hotel Lost and Found.

## Conference Evaluations

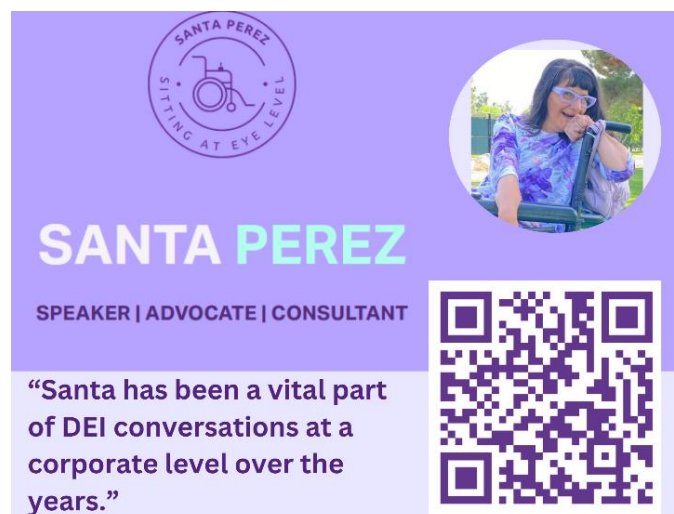
Please help us improve on the NACDD Annual Conference by completing an evaluation which will be available through the platform.

## Audio-Visual Equipment

If you are a speaker who needs assistance with the audio-visual equipment, a member of the NACDD staff will be happy to assist you or connect you with technology staff that can help.

## Navigating the Meeting Space

Please see the hotel floor plan on page 09 to identify the location of the meeting spaces, elevators, and emergency exits. Please look for signage that indicates the name of each session.



A purple profile card for Santa Perez. At the top left is a circular logo with a wheelchair icon and the text "SANTA PEREZ" at the top and "SITTING AT EYE LEVEL" at the bottom. To the right is a circular photo of Santa Perez, a woman with glasses and a purple floral shirt, sitting in a wheelchair. Below the logo and photo, the name "SANTA PEREZ" is written in large, bold, white letters. Underneath the name, the text "SPEAKER | ADVOCATE | CONSULTANT" is written in smaller white letters. At the bottom left, a quote reads: "Santa has been a vital part of DEI conversations at a corporate level over the years." To the right of the quote is a QR code.



## Accommodations

We will provide live CART transcription during the plenary sessions and lunches. In addition, auto-generated captions will be available in the breakout rooms. For any accommodations not requested in advance of the conference, please see NACDD staff at the Registration Table to assist you in meeting an on-site request. Conference materials are on the platform. PowerPoint presentations will be available at [nacdd.org](http://nacdd.org) after the conference.

## Photography Consent Policy

Please be advised that NACDD will photograph and/or record video and/or audio at the Annual Conference and AIDD Technical Assistance Institute. Speakers, attendees, guests, and all others present may be photographed by NACDD. By registering for and attending the Annual Conference, you acknowledge that you have been informed that you may be photographed, video recorded, and/or filmed. You grant NACDD permission, without further notification, to publish photographs and video taken of you and containing your image/likeness for publicity, general information purposes, social media platforms, press releases, etc. If you do not wish to be photographed or videotaped, please notify the photographers or videographers if they approach you.

## Local Hospital

- George Washington University Hospital—10 minutes away (202)- 715-4000
- Howard University Hospital—13 minutes away (202) 865-6100

## Accessible Equipment Rentals

If you are renting equipment, please let NACDD staff know so we can connect you with the appropriate people at the hotel.

- [Mandad Medical Supplies-  
mandadmedical1@gmail.com](mailto:mandadmedical1@gmail.com) - 703-910-6264
- [My Medical House: sales@mymedicalhouse.com](mailto:sales@mymedicalhouse.com) –  
703-214-0462
- [Zask Medical Supply](http://Zask Medical Supply) 703-354-1266
- [Rio Medical Supplies](http://Rio Medical Supplies): 703-931-9600



## What to do in DC?

Scan the QR Code to discover DC's travel site!

# National Disability Independence Day

On behalf of the National Association of Councils on Developmental Disabilities, we are thrilled to celebrate National Disability Independence Day during our annual conference. This day marks a pivotal moment in history, commemorating the signing of the Americans with Disabilities Act (ADA) on July 26, 1990. The ADA has been instrumental in paving the way for greater accessibility, inclusion, and equality for individuals with disabilities across our nation.

This year, our conference theme, "A World of Opportunities," resonates deeply with the essence of National Disability Independence Day. It reminds us that the progress we have made since the ADA's inception is only the beginning. Our commitment to fostering a world where individuals with developmental disabilities have the same opportunities to live, learn, work, and thrive is unwavering.

"A World of Opportunities" is more than a theme; it is a call to action. It challenges us to break down barriers, create inclusive environments, and advocate for policies that support independence and empowerment. As we gather to share knowledge, experiences, and strategies, we are united in our mission to build a future where every person, regardless of ability, has the chance to reach their full potential.

Today, we honor the achievements of the past and look forward with hope and determination. Let us celebrate the strides we have made, acknowledge the work that remains, and continue to champion the rights and opportunities for all individuals with disabilities. Together, we can create a truly inclusive world filled with endless possibilities.

Happy National Disability Independence Day!





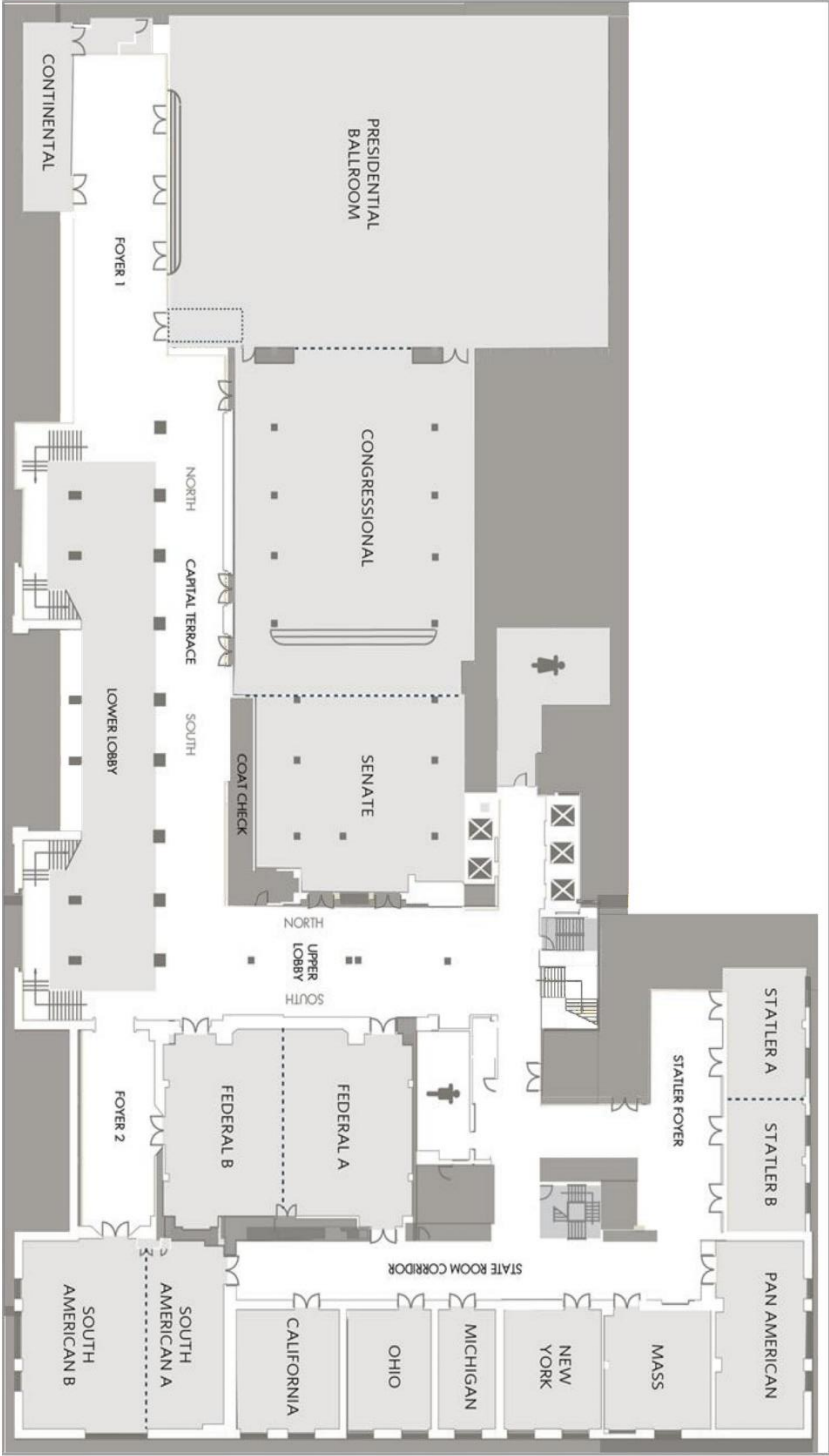
# Reimagining Health Care

INCLUSION | EQUITY | INDEPENDENCE | ADVANCEMENT

  
*CareSource*



# Conference Map





## **RAISING THE BAR**

We are proud to support **NACDD Annual Conference!**

Microsoft's mission is to empower every person and every organization on the planet to achieve more. Working together, we can create a world that's more inclusive, accessible, and equitable for everyone.

[Microsoft.com/accessibility](https://www.microsoft.com/accessibility)



# Daily Conference Schedule

Tuesday July 23<sup>rd</sup>, 2024

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**7:00 AM – 4:00 PM**

**Registration Opens**

**11:30 AM – 1:30 PM**

**Board of Directors Meeting**

*South American B*

**6:00 PM – 8:00 PM**

**Welcome Reception**

*South American AB*

Wednesday July 24<sup>th</sup>, 2024

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**7:00 AM – 4:00 PM**

**Registration**

**7:00 AM – 8:00 AM**

**Breakfast**

*Outside of the Presidential Ballroom*

**9:00 AM**

**Welcome and Opening**

*Presidential Ballroom*



## **9:30 AM – 11:30 AM**

### **State and Territory Showcase**

*South American AB*

## **12:30 PM – 2:30 PM**

### **Participants Lunch on your own**

*Out of Venue*

## **12:30 PM – 2:30 PM**

### **Special Invitation Lunch with Jill Jacobs, Executive Director's and Board of Directors**

*Presidential Ballroom*

## **2:30 PM – 4:00 PM**

### **Breakout Sessions**

### **Empowering Self-Advocates to Lead**

*Federal A*

Self-advocates possess valuable lived experience but are frequently excluded from projects about them. We will present our team's participatory tools and methods, including online training for self-advocates and resources for program staff. These tools enable staff to better support individuals with IDD in their projects. Additionally, we are developing a network to connect self-advocates and project staff. Attendees will be inspired to adopt a participatory approach and gain practical tools and strategies for successful implementation.

**Cynthia Burrow**, Strategic Education Solutions

**James Meadours**, Strategic Education Solutions



## **Not Just "in" the community but "of" the Community**

*Federal B*

How often are our inclusion practices translating to the feeling of being included? A sense of belonging is a cornerstone to building a solid foundation upon which the possibilities of the future can be built. Too often, however, individuals with disabilities are left behind, invalidated, and dismissed, resulting in cracks not only in the foundation of an individual's sense of self, but also in their self-esteem which often forms roadblocks to a fulfilling and purpose-driven life.

**Russell Lehmann**, Author, speaker, advocate

## **It's Their Futures: Advancing Alternatives to Guardianship by Expanding State and National Youth Leadership**

*South American A*

CYVYC's Youth Ambassador program supports State Teams with technical assistance and learning exchanges to promote systems change and share promising practices. It trains Youth Ambassadors with I/DD to educate on self-determination and alternatives to guardianship. This session focuses on CYVYC's program experiences, spotlighting the Texas State Team led by the Texas DD Council and Texas Advocates, highlighting their projects and approaches in advancing alternatives to guardianship.

**Matthew Leos**, Texas Youth Ambassador

**Lauren Gerken**, Texas Developmental Disabilities Council

**Brianna TenBrink**, Texas Developmental Disabilities Council

**Morgan Whitlach**, Center for Public Representation

## **Self-Direction and the I/DD Community: A Look into the Past and Future**

*South American B*

This session discusses the growth of self-direction in the community serving people with autism and developmental and intellectual disabilities. We will examine growth, program designs, individual budgets, and quality performance measures.

**Suzanne Crisp**, Public Partnerships



## **Roses and Thorns: Person-Centered Planning and HCBS**

*Statler AB*

Since 2020, Nebraska’s HCBS recipients have been using the Charting the Lifecourse (CtLC) Framework in the PCP process, thanks to Council investment and advocacy. The CtLC framework supports individuals and families of all abilities and ages in envisioning their good life. This presentation will define and explain Person-Centered Planning (PCP), highlight the benefits of PCP for individuals with I/DD, discuss the shift from traditional decision-making models to person-centered approaches, show how Nebraska's HCBS system integrates the CtLC framework into ISP meetings, and illustrate how collaboration with State agencies drives systemic changes.

**Kristen Larsen**, Nebraska Council on Developmental Disabilities

**Beth Plisek**, Nebraska Council on Developmental Disabilities

**Rachel Ward**, Nebraska Council on Developmental Disabilities

**4:00 PM – 4:30 PM**

**Break**

**4:30 PM – 6:00 PM**

**Breakout Sessions**

## **Sexual Self-Advocacy**

*Federal A*

This panel will provide a platform for Self-Advocate Sexuality Educators to mentor and guide participants, drawing from their wealth of experience as educators. Through interactive discussions and sharing sessions, attendees will learn how self-advocates can leverage their expertise to become leaders in advocating for and teaching sexuality education.

**Max Barrows**, Green Mountain Self-Advocates

**Katherine McLaughlin**, Elevatus Training

**Tia Nelis**, TASH

**Mary Shehan**, Michigan Developmental Disabilities Council

**Frank Vaca**, Michigan Developmental Disabilities Council

**Wesley Witherspoon**, California Developmental Disabilities Council



## **Brains @ Work: The Invisible Power of Neurodiversity**

*Federal B*

In this session, we shine a light on something that is virtually invisible in most organizations: neurodiversity. Brains @Work is a new way to think about structuring your work environment to create deeper employee engagement, more cohesive cultures, and vastly improved productivity.

**Sarah Ohanesian**, Brains @ Work

**Jeff Gibbard**, Brains @ Work

## **Promoting the Mental Well-being of Transition Age Youth with DD**

*Statler AB*

The Meadows Mental Health Policy Institute will present research findings from community convenings and focus groups on mental health needs of transition age youth with developmental disabilities. Recommendations aim to enhance understanding and support across systems (IDD, mental health, schools, crisis services). The goal is to move from discussion to action by engaging communities in identifying solutions for better coordination and effective support.

**Katie Mitten, LMSW**, The Meadows Mental Health Policy Institute

**Rohanna Sykes, LPC-S**, The Meadows Mental Health Policy Institute

## **Cultivating Strength in Loss for Adults with I/DD**

*South American A*

Adults with IDD often face disenfranchised grief due to exclusion from conversations about loss and grief rituals, impacting their mental health. Existing resources for this group are sparse, heightening their risk. This presentation will outline efforts to develop tailored resources addressing disenfranchised grief among adults with IDD, emphasizing a collaborative approach to meet their unique mental health needs.

**Ling DeBellis**, Rice University

**Kathryn Gonzalez**, Rice University



## Teaching, Empowering, and Training on Navigating Sexuality and Healthy Relationships

### *South American B*

Join Julie Hanna and Eric Stoker at the conference to learn about Utah Developmental Disabilities Council's Tetons program. Explore topics like Public vs Private Spaces, communication games, and setting healthy boundaries through fun activities offered in Tetons courses. Discover resources used in classes from Elevatus and Mad Hatter. Ideal for self-advocates and those interested in healthy relationships.

**Julie Hanna**, Utah Developmental Disabilities Council

**Eric Stoker**, Utah Developmental Disabilities Council

**6:00 PM – 7:30 PM**

## **Movie Night**

## West Virginia Documentary Screening and Panel: ‘Coming Home’

### *Presidential Ballroom*

"Coming Home" is crucial to discussing the role of institutions in society. West Virginia closed its last state institution for people with developmental disabilities (DD) in 1998, becoming the 5th state to do so. In 2019, state policymakers began discussing the redevelopment of institutions for people with DD and co-occurring mental health diagnoses, a trend seen nationwide. The documentary highlights the current lives and struggles of those who left institutions and celebrates their resilience post-pandemic.

**Tina Wiseman**, West Virginia Developmental Disabilities Council





Thursday July 25th, 2024

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**7:00 AM**

**Breakfast opens**

*Outside of the Presidential Ballroom*

**9:00 AM – 9:45 AM**

**Keynote by Rylin Rogers, Disability Policy Advisor,  
Microsoft Accessibility**

*Presidential Ballroom*

**9:45 AM – 11:00 AM**

**General Session: Ending Subminimum Wage and 14c**

*Presidential Ballroom*

**11:00 AM – 11:45 AM**

**Break**

*Outside of the Presidential Ballroom*

**11:45 AM – 1:45 PM**

**Champion of Equal Opportunity Awards Lunch & Keynote  
with Jose Rosario**

*Presidential Ballroom*

**1:45 PM – 2:00 PM**

**Break**



**2:00 PM – 3:30 PM**

**Breakout Sessions**

**Improving Data for Health Equity for People with I/DD**

*Federal A*

This session focuses on efforts by the Administration for Community Living (ACL) and the National Center on Birth Defects and Developmental Disabilities (NCBDDD) to improve data collection and achieve health equity for the I/DD population. One mechanism being considered is to create a Center(s) of Excellence on I/DD Data. ACL and NCBDDD through a contract with Human Services Research Institute is working with federal and community partners for feedback on the best design for a proposed Center. ACL knows the importance of DD prevalence for program funding and is working on prevalence of I/DD in collaboration with the National Center for Health Statistics. We are soliciting feedback on improving data on prevalence, health outcomes and beyond.

**Alixé Bonardi**, Human Services Research Institute

**Andrew Morris**, IDD Counts

**Heather Young**, Human Services Research Institute

**The Benefit of Self-Advocate Story Telling in Medical Education**

*Federal B*

This session explores how self-advocates collaborated via a Community Advisory Board to co-design and co-present a didactic series for family medicine residents on intellectual and developmental disabilities care. It emphasizes the mutual benefits of including self-advocates in medical education for both advocates and learners alike.

**Kaitlyn Davis, MS, MPH**, Thomas Jefferson University

**Joan Thomas**, Parent & serves on the Jefferson FAB Center for Complex Care's Community Advisory Board

**John Thomas**, Self-Advocate & Member of the Jefferson FAB Center for Complex Care's Community Advisory Board



## The Lives of LGBTQ+ People with Developmental Disabilities

*Statler AB*

People with developmental disabilities deserve equal opportunities to express their gender and sexuality. LGBTQ+ individuals within this community often lack necessary support due to societal discomfort with these topics. By sharing stories and perspectives of LGBTQ+ individuals with developmental disabilities, I aim to foster understanding, promote self-expression, and advocate for our rights together.

**Pauline Bosma**, Rainbow Support Groups of Massachusetts

## Walking the Walk: Building Professional Careers for Self-Advocates within Disability Organizations

*South American AB*

Self-Advocates want to do more than serve on advisory committees. They want careers! Maxwell Barrows and Hasan Ko have held a variety of positions over the past 17 years at Green Mountain Self-Advocates. Presenters will introduce strategies, tips, and tools for a more inclusive workplace that supports people with disabilities to have professional jobs within our field. Self-Advocates often encounter a “glass ceiling” when they try to advance in their careers, even within disability organizations. If our disability movement is truly going to embrace the concept of Nothing About Us Without Us, more people with intellectual disabilities need professional opportunities.

**Max Barrows**, Green Mountain Self-Advocates

**Hasan Ko**, Vermont Developmental Disabilities Council

**Karen Topper**, Green Mountain Self-Advocates

**3:30 PM – 4:00 PM**

**Break**

**4:00 PM – 5:30 PM**

**Breakout Sessions**



## **A Mother's Perspective: The Special Education Challenge for Immigrant Families and the Power of Diverse Leadership**

*Federal A*

Because the needs of children who require special education are much more difficult to advocate for when they are from underrepresented and underserved communities. This is especially difficult for those families who are not native English speaking.

**Asha Abdullahi**, Massachusetts Developmental Disabilities Council

**Cynthia Laine**, Massachusetts Developmental Disabilities Council

**Rael Quezada**, Massachusetts Developmental Disabilities Council

## **College & Councils: How Inclusive Post Secondary Education and State DD Councils Make Each Other Stronger**

*Federal B*

IPSE supports college students with intellectual disabilities, offering academics, social networks, job skills, and life skills crucial for independent adult life. GCDD has built key policy making connections through IPSE, enhancing state-level disability advocacy. Join our interactive session to explore IPSE connections in your state, hear from graduates and students, and learn how GCDD leverages IPSE for community advancement.

**Starr Bruner**, Georgia Developmental Disabilities Council

**D'Arcy Robb**, Georgia Developmental Disabilities Council

**Darien Todd**, Center for Leadership in

## **Advocating for and Expanding the Use of Plain Language**

*South American AB*

We aim for people with disabilities to access clear, plain-language information for informed decision-making. Developmental Disabilities Councils increasingly adopt plain language. How can we engage state self-advocacy groups, agencies, providers, and advocates in this effort? Learn from Wisconsin Council board and staff members about their plain language initiatives in this session.

**Sydney Badeau**, Self-Advocate

**Molly Cooney**, Wisconsin Developmental Disabilities Council



## North Dakota's Peer Model

*Statler AB*

This panel presentation will focus on different perspectives for implementing the peer-to-peer program throughout the education system, from middle school to higher education. There will also be a discussion on the philosophy of the program, how it was created with individual and family perspectives, and will include curriculum discussion so others could easily implement a similar program in their state.

**Mandi Eberle, M.Ed.**, Bismark State College

**Sheila Peterson**, Wachter Middle School

**Roxanne Romanick**, Social Worker

**6:00 PM – 8:00 PM**

## **Movie Night**

### 'Divided Attention: When the children who need the most, receive the least – An Emmy-nominated Documentary Film' Pennsylvania Documentary Screening and Panel

*South American AB*

Delaware County Advocacy & Resource Organization (DCARO)'s Divided Attention documentary film, funded through a grant from the Pennsylvania Developmental Disabilities Council, follows four students from Toby Farms, a public middle school in the historically underfunded Chester Upland School District, as they learn and practice mindfulness amidst the COVID-19 pandemic, the school to prison pipeline, and threat of charter takeover.

**Eileen MacDonald**, Delaware County Advocacy & Resource Organization

**Stacey Mandel**, Public Health Management Corporation

**Nicole Mendez**, Pennsylvania Inclusion Collective

**Stephanie Ramos**, Director

**Lisa A. Tesler**, Pennsylvania Developmental Disabilities Council



Friday July 26th, 2024

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**7:00 AM – 9:00 AM**

**Breakfast**

*Outside of the South American AB*

**7:30 AM – 9:00 AM**

**Self-Advocates Breakfast with Jill Jacobs**

*Statler AB*

**7:30 AM – 9:00 AM**

**IDD Counts focus group**

*Federal A*

**9:00 AM – 10:00 AM**

**General Session - Annie Ray, Annandale High School Music Teacher and Grammy Award Winner**

*South American AB*

**10:00 AM – 11:30 AM**

**General Session - The weather is Getting Worse-- How to Prepare—FEMA ODIC**

*South American AB*

**11:30 AM**

**Boxed lunch will be served**

*Outside of the South American AB*



**12:00 PM – 1:30 PM**

## **Breakout Sessions**

### **Empowered to Rise**

*Federal A*

Speaker Jose Rosario shares his personal experiences with systemic inequality and stigma, highlighting the connection between identity and mental health. He encourages attendees to reflect on their own identities and their impact on personal and professional relationships, increasing understanding of the effects of identity, stigma, and discrimination on mental health. Additionally, attendees will explore ways to engage in long-term, intentional allyship and change.

**Jose Rosario**, Advocate

### **Lived Experience in Leadership: ALP-NC's Innovative**

#### **Advocacy Program**

*South American AB*

Join us to explore the groundbreaking Ability Leadership Program of North Carolina (ALP-NC), administered by Community Bridges in partnership with the North Carolina Council on Developmental Disabilities. This session will detail how ALP-NC educates and empowers individuals with intellectual and developmental disabilities (I/DD), their families, and professionals, fostering a robust network of advocates. We will also highlight the value and impact of employing consultants with IDD to facilitate and administer the program model, one of ALP-NC's key differentiators.

**Cameron Kempson**, MEd, Community Bridges

**Hannah Shumaker**, MEd, LCMHCA, Community Bridges

**Talley Wells**, North Carolina Developmental Disabilities Council



## **Vamos DC: Supporting the Latino Disability Community** **Living in DC**

*Statler AB*

Discover Vamos DC, an initiative tailored for DC's Latino disability community, addressing their cultural needs through a collaboration between the District government and local organizations. Explore how Vamos DC builds community trust and influences significant changes in the DC DD Council and disability services. Hear firsthand accounts from community members about their experiences with Vamos DC.

\*Please note that this session will be presented in Spanish. We will have listening devices for those who need translation

**Andrés Alejandro**, DC Developmental Disabilities Council

**Berta Mata**, DC Developmental Disabilities Council

**Carla McCaskill**, DC Developmental Disabilities Council



# NACDD Staff Information



The National Association of Councils on Developmental Disabilities (NACDD) is the national association for the 56 Councils on Developmental Disabilities (DD Councils) across the United States and its territories. The DD Councils receive federal funding to support programs that promote self-determination, integration, and inclusion for all people in the United States with developmental disabilities.

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**Thank you for  
joining us!**



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