Monday, July 24, 2023

**8:00am- 12:00pm.**

**ITACC Minimum Allotment Fiscal workshop**

**11:00am- 6:00pm.**

**Bridging Aging and Disability Networks CoP Year 2**

**1:00pm- 6:00pm**

**New ED Orientation**

Tuesday July 25, 2023

**9:00am — 12:30 p.m.**

**ITACC Chairperson Leadership Training**

**9:00am — 5:30 p.m.**

**Bridging Aging and Disability Networks CoP Year 2 day 2**

**11:00am — 1:00 p.m.**

**NACDD Board Of Directors Call**

**1:30pm — 5:30 p.m.**

**ITACC Chairperson Leadership Training with Eds**

**6:00pm — 8:00 p.m.**

**WELCOME RECEPTION**

**Wednesday, July 26, 2023**

**8:00am- 9:30am Breakfast served.**

**9:00am- 9:30am**

**Welcome to the 2023 NACDD Annual Conference**

**9:30am- 11:00am**

**Opening Keynote address**

**11:00am- 11:30am**

**Break**

**11:30am-1:00pm**

**General Session**

**1:00pm- 2:30pm**

**Networking Lunch with small presentation**

**2:30pm- 3:00pm**

**Break**

**3:00pm- 6:00pm-- WORKSHOPS**

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| **Being a Sexual Self-Advocate and Teaching Others**  We know that people with I/DD often lack basic sexuality education knowledge and skills which leads to many negative outcomes. We also know that having people with a shared/lived experience makes a difference in how the education is received. In this workshop, we will teach self-advocates the knowledge and skills needed to support, educate and provide resources for other people with disabilities.  **Katherine McLaughlin, Elevatus**  **Mary Shehan-Boogard,** Michigan DD Council  **Tia Nelis**, TASH  **Frank Vaca**, Michigan Advocates |
| **Storytelling—Learning to tell my story and Learning to write a story**  Councils all share the desire to educate, advocate, and inform their communities about topics that are important to people with developmental disabilities and their families. Reaching out to legislators, people with disabilities, family members, news media, and allies is a key strategy. This session will describe how the use of a documentary featuring individuals with developmental disabilities can be a powerful advocacy and education tool.  **Delaware DD Council**  **Cow Tipping Press** |
| **Civic Engagement and me**  Participants will learn about ways to ensure they can vote and also how to speak with policymakers.  Scott Daigle, Texas DD Council  Selene Gomez, VoteRiders |

**6:00pm- 7:00pm**

**Closing Reception hosted by PPL**

**Thursday, July 27, 2023**

**8:00am- 9:00am**

**Breakfast**

**8:30am- 10:00am**

**General Session**

**10:00am- 10:30am**

**Break**

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| **10:30am — 12:00pm**  **Concurrent Sessions:**  **CYVYC**  This session shares how the ICI has engaged with youth and young adults with IDD around advocacy and research through three key projects: 1) [CYVYC](https://youth-voice.org/), 2) [GATOR](https://gator.communityinclusion.org/), and 3) [College Matters Florida](https://collegemattersflorida.org/), a project funded by the Florida Developmental Disabilities Council. The ICI has been innovative in its approach to training youth and young adults with IDD to become ambassadors in promoting both alternatives to guardianship (CYVYC) and postsecondary education (College Matters Florida). ICI has also partnered with young adults with IDD from [MASS](https://www.wearemass.org/) and [SANYS](https://sanys.org/) to work alongside project staff as co-researchers. These researchers brought their expertise, perspectives, and lived experiences to multiple stages of the research process, making project findings and products richer and more useful to our intended audiences. Within the CYVYC project in particular, ICI partnered with [Self Advocates Becoming Empowered](https://www.sabeusa.org/), who co-developed and co-implemented the [YA curriculum](https://youth-voice.org/youth-ambassador-curriculum/). Having a [cadre of trainers](https://youth-voice.org/meet-the-trainers/) with lived experience training youth with IDD about alternatives to guardianship and supported decision-making created a space where the youth not only received information, but they also got to hear from people who have experienced many of the same things they are experiencing and navigated the same paths they are working to navigate, making a big difference in the receptivity and engagement of the participants. All three projects represent the “Nothing About Us Without Us” model in both research and advocacy, ensuring that people with IDD get “beyond the conversation” and join professionals in promoting the topics they feel passionate about.  Daria Domain et al.  **Start Early- Karen Berman**  Research is clear on the importance of the earliest years in a child’s life for their development and ability to reach their greatest potential in school and life. While federal laws and powerful guidance from federal agencies support access to high quality inclusive experiences for children with delays and disabilities, families still face significant barriers in accessing services. This session will provide an opportunity for participants to understand how they can take action through their Councils on Developmental Disabilities (DD Councils) to support innovative and impactful strategies to improve the systems that impact our youngest children with developmental disabilities and delays and their families. The session will highlight work that advocates in Illinois have been able to do in partnership with policymakers, providers, and families with investment from the Illinois Council on Developmental Disabilities to improve early childhood inclusion across birth to 5 settings and to improve connections to Early Intervention for children exiting NICUs.  The presentation will include parents with young children with developmental delays and disabilities and early childhood providers and teachers who can speak powerfully to their lived experiences and how these efforts are impacting them and their communities. Participants will be provided tangible examples for advocacy in their states, and opportunities for collaboration across states to achieve even greater impact. Participants will have opportunities to engage in discussion and will leave with actionable next steps, tools, and resources.  **Patient and Family Advisory Councils and Cooper University**  This session will showcase how the partnership between Cooper University Healthcare, a Patient Family Advisory Council and local government and state offices can inform, build and support a system of care for adult patients with intellectual and developmental disabilities who require additional resources and specialized care.  We believe that sharing our developing program at Cooper University Healthcare will increase awareness of what PFAC’s and healthcare organizations can do together to support the pediatric and adult patient populations with intellectual and developmental disabilities. It exemplifies how important patient and family advocacy is to initiate these programs and give a voice to our patients who cannot speak for themselves.  Dr. Jovin et. al  **Texas Advocates**  This session will provide a description and critical analysis of Texas Advocates’ Peer Mentoring for Institutionalized Individuals with IDD and Nex Chapter Book Club Projects, which the organization has been implementing since 2018 including throughout the COVID-19 pandemic. Presenter Brooke Hohfeld, the Project Director and co-Executive Director of Texas Advocates, is an individual with an intellectual disability who assumed leadership of the initiative in its second year. Presenter Holly VanScoy serves as Texas Advocates Program Development and Evaluation counsel and has been involved in the assessment of the both of these projects’ outcomes from the beginning. Both Hohfeld and VanScoy developed the SALT Program, launched in December 2022, and have early results of this project to share.  Evaluations have tracked the mentoring project’s progress from delivering in-person mentoring services on the campuses of two of Texas’ SSLCs, through a period of virtual group meetings, and into its final iteration of delivering individualized mentoring to adults residing in an SSLC and in ICFs, as well as the NCBCs from formation through maturity. The barriers encountered in each service delivery model will be described, as well as the solutions Texas Advocates devised to address each of the challenges it faced.  In addition, the session will provide information about the multiple approaches to training provided to the mentors and NCBC facilitators, and how these promoted these individuals’ development of knowledge, skills, and self-confidence in these roles.  The session will provide attendees with an opportunity to ask questions about the project to either or both presenters. |

**12:30pm- 2:30pm**

**Champions of Equal Opportunity Awards Lunch hosted by Optum**

2:30pm- 3:00pm

Break

3:00pm- 430pm

General Session

4:30pm- 4:45pm

Break

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| **4:45pm — 6:15pm**  **Concurrent Sessions:** |
| **Bev Weinberg**  This session shares how the ICI has engaged with youth and young adults with IDD around advocacy and research through three key projects: 1) [CYVYC](https://youth-voice.org/), 2) [GATOR](https://gator.communityinclusion.org/), and 3) [College Matters Florida](https://collegemattersflorida.org/), a project funded by the Florida Developmental Disabilities Council. The ICI has been innovative in its approach to training youth and young adults with IDD to become ambassadors in promoting both alternatives to guardianship (CYVYC) and postsecondary education (College Matters Florida). ICI has also partnered with young adults with IDD from [MASS](https://www.wearemass.org/) and [SANYS](https://sanys.org/) to work alongside project staff as co-researchers. These researchers brought their expertise, perspectives, and lived experiences to multiple stages of the research process, making project findings and products richer and more useful to our intended audiences. Within the CYVYC project in particular, ICI partnered with [Self Advocates Becoming Empowered](https://www.sabeusa.org/), who co-developed and co-implemented the [YA curriculum](https://youth-voice.org/youth-ambassador-curriculum/). Having a [cadre of trainers](https://youth-voice.org/meet-the-trainers/) with lived experience training youth with IDD about alternatives to guardianship and supported decision-making created a space where the youth not only received information, but they also got to hear from people who have experienced many of the same things they are experiencing and navigated the same paths they are working to navigate, making a big difference in the receptivity and engagement of the participants. All three projects represent the “Nothing About Us Without Us” model in both research and advocacy, ensuring that people with IDD get “beyond the conversation” and join professionals in promoting the topics they feel passionate about.  Daria Domain et al. |
| **Amy Jedele**  In this session, we will show how the Housing Demonstration Project supported with funds from the PA Developmental Disabilities Council has partnered with a variety of stakeholders to demonstrate a comprehensive, person-directed housing model that ensures people with developmental disabilities can legally control their own housing, choosing where and with whom to live, and ensuring that the housing is separate from their service provision.  We will share strategizes for outreaching to all stakeholders, including people with developmental disabilities, families, supports coordinators, generic housing industry representatives, and state officials to increase their understanding of available services, challenges to accessing affordable housing, and recommendations for system wide improvements.  Attendees will gain access to the Finally Home Housing Toolkit User Guide, including the Housing Assessment, Person Centered Housing Plan, training modules that can be customized for use in their communities, and an overview of Pennsylvania’s Housing Transition & Tenancy Sustaining service available through the I/DD waiver.  The result of the Project was the implementation of a Housing Symposium to share lessons learned, identify key next steps, and to engage with state and national representatives to continue the conversation. |
| **Drew Webster**  This session will showcase how the partnership between Cooper University Healthcare, a Patient Family Advisory Council and local government and state offices can inform, build and support a system of care for adult patients with intellectual and developmental disabilities who require additional resources and specialized care.  We believe that sharing our developing program at Cooper University Healthcare will increase awareness of what PFAC’s and healthcare organizations can do together to support the pediatric and adult patient populations with intellectual and developmental disabilities. It exemplifies how important patient and family advocacy is to initiate these programs and give a voice to our patients who cannot speak for themselves.  Dr. Jovin et. al |
| **I Have Rights—Alaska Advocates**  **I Have Rights** presentation brings together individuals with disabilities as panelists to talk about their rights and be an open forum for others in the audience to share as well. This presentation will introduce the guide produced by the Alaska Governor's Council on Disabilities and Special Education and the Senior and Disabilities Services Division, called Living Well: I Have Rights. We will go over the new guide, go into discussion, and have a Question-and-Answer session.  This event is for people with disabilities (focusing on developmental disabilities but including other forms), their parents/guardians, as well as service providers who want to know more about their rights. Specific topics covered will include access to services, making personal choices, community participation, respect and dignity, an individual’s privacy, personal safety, education, and employment choices. There will also be an opportunity to discuss dreams and accomplishments, how they can be incorporated into home and community-based living/services, and look forward to a future that is more person-directed as well. This presentation is geared toward advocates taking action in their own lives. |

Friday, July 28, 2023

**7:00am- 8:30am**

**Breakfast served**

**8:00am- 9:00am**

**NACDD General Assembly Meeting**

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| **9:00am- 10:30am**  **Concurrent Sessions:** |
| **North Carolina with Kelly Friedlander**  In recent years, the North Carolina Council on Developmental Disabilities (NCCDD) has dedicated efforts towards championing the significance of lived experience in a variety of advocacy, leadership, and employment contexts. This presentation will concentrate on pivotal initiatives that have facilitated the development of professional, compensated opportunities for individuals with intellectual and developmental disabilities (I/DD) in North Carolina.  ● The Peer Mentor Training Program for Individuals with Intellectual and Developmental Disabilities: The NCCDD, in collaboration with Optum and the National Association of Councils on Developmental  Disabilities (NACDD), introduced and piloted an innovative peer training curriculum tailored for  individuals with intellectual and/or developmental disabilities residing in the community who utilize  Home and Community-Based Services (HCBS).  ● Mission Possible: Advancing Whole Person Care by Employing People with I/DD & Family Members as Care Extenders: This initiative's objective was to produce a Care Extender Paper that encapsulates the viewpoints of diverse stakeholders, including families, individuals with I/DD, LME MCOs, DD providers, policymakers, and healthcare providers. Additionally, the paper outlines strategic recommendations for addressing potential obstacles that could impede success.  The presentation will underscore how these initiatives have effectively transformed the concept of lived experience from mere conversation to concrete actions. Building upon one another, these initiatives have generated momentum for policy alterations and improved practices, empowering individuals with I/DD and their family members to secure employment and assume leadership roles within various systems supporting the developmental disability community. |
| **Pamela Zotynia- HOUSING IN PA**  In this session, we will show how the Housing Demonstration Project supported with funds from the PA Developmental Disabilities Council has partnered with a variety of stakeholders to demonstrate a comprehensive, person-directed housing model that ensures people with developmental disabilities can legally control their own housing, choosing where and with whom to live, and ensuring that the housing is separate from their service provision.  We will share strategizes for outreaching to all stakeholders, including people with developmental disabilities, families, supports coordinators, generic housing industry representatives, and state officials to increase their understanding of available services, challenges to accessing affordable housing, and recommendations for system wide improvements.  Attendees will gain access to the Finally Home Housing Toolkit User Guide, including the Housing Assessment, Person Centered Housing Plan, training modules that can be customized for use in their communities, and an overview of Pennsylvania’s Housing Transition & Tenancy Sustaining service available through the I/DD waiver.  The result of the Project was the implementation of a Housing Symposium to share lessons learned, identify key next steps, and to engage with state and national representatives to continue the conversation. |
| **CareSource**  TBD |
| **Living a Self-Directed Life**  Sydney and Eric |

10:30am- 10:45am

Break

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| **11:00am- 12:30pm**  **Concurrent Sessions:** |
| **Improving Postsecondary Outcomes: Florida’s Targeted Disparity Initiative for Improving Access to and Completion of Postsecondary Education Programs**  The population of individuals identified with autism spectrum disorder (ASD) is significantly growing, as is the population of youth who identify as Hispanic/Latino, with many of these youth speaking Spanish as their first language. To address disparities found in access to and completion of postsecondary education, particularly in the realm of state colleges (i.e., community colleges) for these youth, the Florida Developmental Disabilities Council implemented a 4-year project in partnership with the University of Central Florida, Center for Autism and Related Disabilities.  The project’s work has resulted in significant improvements. This session will include an examination of the extensive research; promising practices and tools developed as a result of the research findings for all constituents (i.e., secondary and postsecondary students, families, secondary and postsecondary educators, and others); and most importantly, the positive outcomes of the project. Participants will hear first-hand from Council staff, the Project Coordinator, and a state college graduate who provided input into the project, and who used the promising practices and tools developed by the project to successfully earn certificates and complete a state college program. Participants will leave this session with new knowledge, immediate access to the promising practices and tools, and the capacity for replication to achieve positive improvements in their own states.   1. Include why this session is important:  * This session provides insight into barriers and solutions and offers replicable resources that states may use to improve access to and completion of postsecondary education programs by youth who identify as ASD and Hispanic/Latino.  1. How is it relevant to the theme of the conference “Beyond the Conversation**”?**  * This session conveys how engaging diverse groups, including individuals who identify as ASD and Hispanic/Latino and their families, in all facets of work (e.g., research to identify barriers and solutions, immersion in developing promising practices and tools, feedback on application of resources and tools) enabled the Council to address identified disparities by putting our stakeholders’ ideas into action and achieving positive systemic change and improved individual outcomes. |
| **Transition Discoveries Framework**  Our initiative has taken the Transition Discoveries Framework and moved to real-world practice through the development of multi-step model where youth, families and transition stakeholders co-lead the evaluation of transition in their community. Together, they identify strengths and capitalize upon them to design and fully implement improvements to areas of needed support. Often, gaining a clear picture of a complex system can be a significant challenge, and even more so, ensuring that all voices are heard equally – youth, families, and stakeholders – so that all silos of knowledge are linked together. To support this work, we have developed a serious of universally designed tools to gather information about effective transition, areas for improvement and potential implementation factors. Most importantly, the knowledge gained by communities using these tools has empowered them to develop unique strategies for relationship-building and empowerment for youth and families. We have taken what was once a conversation over the importance of youth empowerment in systems and have gone ***beyond the conversation*** to bring these passions to real world implementation. |
| **Community Inclusion, Disability in the greater Civil Rights conversation: an Idaho case study**    Council members from the Latino community in Idaho will present how language barriers and other issues they face make accessing services for people with disabilities extremely difficult. Council members will present the work they have done as family advocates and as a person with a developmental disability. The three council members will speak about the success they are beginning to see as a result of their work.  The lack of inclusion of diverse communities is often discussed, and we often hear from organizations about their plans to include diverse communities and their efforts to become more inclusive. We rarely hear directly from members of diverse communities speak about the real needs that exist in their communities. It is uncommon to see members of such communities leading and take action because they have never been afforded the option to do so. Three Idaho DD Council members with support from the staff at the DD Council have been doing the work of making needed changes through advocacy, leadership development and proposing changes to the system to better meet the needs of the Latino community.  2. How is it relevant to the theme of the conference “Beyond the Conversation**”?**  Idaho DD council members from the Latino community know firsthand how to identify issues that our state faces and propose changes to overcome those issues. These council members have been talking with others in the Latino community about the lack of language access in Idaho and how that barrier makes it difficult, if not impossible for Latinos with developmental disabilities to receive the services they are entitled to. No one has acted on this matter until now. The three council members will talk about the things they have achieved as a result of the action they have taken beyond talking about issues that the disability community faces. They will discuss how the action they took in Idaho is resulting in system changes that will benefit the disability community, the Spanish speaking community, other non-English speaking community members and the entire state.  Miguel Juarez  Marilu Moreno  Maria Juarez  Edgar Zuniga |
| **Renee Hall and Michigan Advocates**  Historically the advocacy movement in Michigan has been lead by advocacy groups without people with lived experience taking the lead. While self-advocates may have been involved, other advocates and allies still held prominent roles of leadership and power. That’s changing here. Self-Advocates of Michigan is going beyond talking about self-advocates leading and the self-advocates are *actually leading*. Statewide they have a Board of Directors comprised soley of people who identify as having a developmental disability and now they are working to implement community based local chapters. These local chapters will feed the Board membership so that communities are well represented in the statewide leadership. The local groups will be involved in policy issues and other issues that impact people with DD in the places they live, work and play. |

12:30pm- 1:30pm

Lunch and Entrepreneurship with Aarti Saghal

1:30pm

Thank you and See you next year!