WELCOME

2019 UCEDD Directors Retreat

Long range planning does not deal with future decisions, but with the future of present decisions.

– Peter F. Drucker
• Share information about Board activities, financial health of AUCD, and key policy updates
• Host a space for network leadership to address pressing issues
  – In collaboration with peers and AUCD staff
  – In absence of federal funders
AUCD Board Updates
AUCD Board Updates

• Upcoming Board of Director calls
  – Board members will be reaching out to all UCEDD, LEND, IDDRC Directors
• Current Board discussion:
  – Approach to private sector fundraising
  – Meeting network needs in international work
  – Ensuring focus on IDD while also working cross-disability
• Upcoming bylaws change requests
  – Board size changed from 19 to 16, with option for up to 20
  – Adding a voting role for emerging leader/early career professional
  – Create consistency with how everyone comes on to the Board and is eligible for Board Officer roles
• Board voted for dues increase (2%) effective new fiscal year - July 1
  – First increase since 2016
  – Costs of doing business has increased
  – UCEDD core grants went up in the budget bill from $547,000 to $570,000.
**Multi-Year Net Assets Results (In Millions of USD)**

*Adjusted Budget Projections for 2019*

<table>
<thead>
<tr>
<th>Year</th>
<th>Total Revenue - USD (Millions)</th>
<th>Net Assets - USD (Millions)</th>
</tr>
</thead>
<tbody>
<tr>
<td>June 2009</td>
<td>4.5</td>
<td>1.0</td>
</tr>
<tr>
<td>June 2010</td>
<td>6.8</td>
<td>1.2</td>
</tr>
<tr>
<td>June 2011</td>
<td>7.7</td>
<td>1.5</td>
</tr>
<tr>
<td>June 2012</td>
<td>8.4</td>
<td>1.8</td>
</tr>
<tr>
<td>June 2013</td>
<td>5.3</td>
<td>1.8</td>
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<tr>
<td>June 2014</td>
<td>3.4</td>
<td>1.8</td>
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<tr>
<td>June 2015</td>
<td>3.9</td>
<td>1.7</td>
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<tr>
<td>June 2016</td>
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<td>2.3</td>
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<tr>
<td>June 2017</td>
<td>6.2</td>
<td>2.3</td>
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<tr>
<td>June 2018</td>
<td>7.5</td>
<td>2.0</td>
</tr>
<tr>
<td>June 2019*</td>
<td>6.4</td>
<td>2.0</td>
</tr>
</tbody>
</table>
Funding Passed to Membership

- Funding passed to Membership
- Grants/Contracts

*Adjusted Budget Projections for 2019
Questions?
AUCD Policy Updates
Political context

• Divided Congress
  – Democratic Control of House
  – Narrow Republican Control in Senate
• Very partisan and divisive
• Unconventional Presidential Administration
• Race for 2020
  – Slows things down; votes are tied to campaigns
U.S. Congress – 116th Congress

House of Representatives
- 253 Democrats
- 198 Republicans
- 1 vacant
- 1 disputed

Senate
- 45 Democrats
- 53 Republicans
- 2 Independents
Budget Timeline

How it is supposed to happen...

- President submits budget – usually early February
- Congress enacts concurrent Budget Resolution – by April 15
- Budget reconciliation
- 302(b) allocations
- H&S agree on 13 annual appropriations bills – Sept.
- Fiscal year begins Oct. 1
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• H&S agree on 13 annual appropriations bills – Sept.
• Fiscal year begins Oct. 1
• President’s Budget Released March 11th
• Full details released on March 18th
• Appropriations under way
  – Increased ask for LEND/UCEDD
  – Maintain PNS
    ▪ House request/“Dear Colleagues” letters process starting
    ▪ Senate request/“Dear Colleagues” letter process starting
The Autism CARES Act

- has expanded research and coordination
- increased public awareness and surveillance
- expanded interdisciplinary health professional training, including LENDs
to identify and support people with Autism and their families

will sunset (expire) in September 2019 without a successful reauthorization.

Bills to reauthorize the Act have been introduced and need co-sponsors (HR. 1058, S. 427)
And…

- **Education**
  - Higher Ed ACT
  - KASSA
  - School Safety

- **Civil Rights**
  - DIA
  - Right to Communicate
  - REDI

- **Employment**
  - Transformation CIE
  - Raise the Wage

- **Health Care**
  - LTSS
  - RX Prices
  - Universal
Let the Retreat Begin!
• **Brainstorm** topics for discussions
  – Single topic can span both discussion times, if needed
• **Facilitators volunteer** to host discussions
• **Assign location** for each discussion based on how many people want to join each topic
• **Discussion approach** to be identified within each individual group, in keeping with “open space”
• **Timekeeping** done by AUCD staff in each discussion
• **Reporter** identified in each group to share takeaways at end of day
Ideas for topical discussions:
<table>
<thead>
<tr>
<th>Before Lunch</th>
<th>11:15-12:15</th>
</tr>
</thead>
<tbody>
<tr>
<td>Topic &amp; Facilitator</td>
<td>Location</td>
</tr>
<tr>
<td>Adams A</td>
<td>Adams A</td>
</tr>
<tr>
<td>Adams B</td>
<td>Adams B</td>
</tr>
<tr>
<td>Mt. Vernon – left</td>
<td>Mt. Vernon – left</td>
</tr>
<tr>
<td>Mt. Vernon - right</td>
<td>Mt. Vernon - right</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>After Lunch</th>
<th>1:45-2:45</th>
</tr>
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<tbody>
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<td>Mt. Vernon - right</td>
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What are the big take-aways from small group discussions?

What will we do with these ideas?
VIP Attendees at the *AUCD For All 2019 Gala*

Disability Community and Policy Leaders

- **Ted Asbury**, VP & Executive Director, Marriott Foundation for People with Disabilities
- **Alison Barkoff**, Director of Advocacy, Center for Public Representation
- **Dan Berland**, Director of Federal Policy, NASDDDS
- **Helena Berger**, President and CEO, American Association of People with Disabilities (AAPD)
- **Kathy Brill**, Executive Director, Parent 2 Parent USA
- **Kelly Buckland**, Executive Director, National Council on Independent Living (NCIL)
- **Bobbi Cordano**, President, Gallaudet University
- **Curt Decker**, Executive Director, National Disability Rights Network (NDRN)
- **Stephanie Enyart**, Chief Public Policy and Research Officer, American Federation for the Blind
- **Chai Feldblum**, former Commissioner, U.S. EEOC
- **Connie Garner**, former Policy Director, Senate HELP Committee, U.S. Senator Edward M. Kennedy
- **Nancy Gennen**, CEO, Galt Foundation
- **Carol Glazer**, President, National Organization on Disability (NOD)
- **Karen Herson**, President and Founder, Concepts, Inc.
- **Eve Hill**, former Deputy Assistant Attorney General, Civil Rights Division, Department of Justice
- **Cathy Holahan**, Senior Legal and Policy Advisor, EducationCounsel, LLC
- **Jill Houghton**, President and CEO, Disability:IN
- **Elain Katz**, Sr. VP, Grants and Communications, Kessler Foundation
- **Bethany Lilly**, Deputy Director, Policy and Legal Advocacy, Bazelon Center for Mental Health Law
- **Kevin Lynch**, President and CEO, National Industries for the Blind
- **Sandy Markwood**, CEO, National Association of Area Agencies on Aging (n4a)
- **Donna Meltzer**, Executive Director, National Association of Councils on Developmental Disabilities (NACDD)
- **Barbara Merrill**, CEO, American Network of Community Options and Resources (ANCOR)
- **Christina Metzler**, Chief Public Affairs Officer, The American Occupational Therapy Association, Inc. (AOTA)
- **Meg O’Connell**, CEO and Founder, Global Disability Inclusion
- **Julie Ward**, Sr. Executive Officer, Public Policy, The Arc of the United States
- **Robin Troutman**, Deputy Director, Operations, National Association of Councils on Developmental Disabilities (NACDD)
- **Jonathan Young**, former Chair, National Council on Disability
VIP Attendees at the *AUCD For All 2019 Gala*

**Gala Honorees:**
- **Tom Ridge**, former Governor of Pennsylvania and Secretary of Homeland Security
- **Bobby Scott**, U.S. Representative (D-VA)
  - Award being presented by Kimberly Knackstedt

**Government Leaders**
- **Michael Gamel-McCormick**, Disability Policy Director, U.S. Sen. Bob Casey (D-PA)
- **Catherine Lhamon**, Chair, U.S. Commission on Civil Rights
- **Neil Romano**, Chairman, National Council on Disability
- **Patrick Mannix**, Chief of Staff, Office of the Assistant Secretary, Office of Disability Employment Policy, U.S. Department of Labor
- **Taryn Williams**, Policy Advisor, Office of the Assistant Secretary, Office of Disability Employment, U.S. Department of Labor, and former Obama White House Disability Advisor
- **Ted Jackson**, Disability Outreach Director, Democratic National Committee
- **Stephanie Fell**, Office of Disability Integration and Coordination, U.S. Federal Emergency Management Agency
- **Rebekah Tosado**, Director of the Antidiscrimination Group (ADG), U.S. Department of Homeland Security, Office for Civil Rights and Civil Liberties

**AUCD Board members:**
- **Amy Hewitt**, President, UCEDD and LEND Director, Institute on Community Integration, University of Minnesota
- **Bruce Keisling**, Past-President, UCEDD Director, Boling Center for Developmental Disabilities, University of Tennessee Health Science Center
- **Sachin Pavithran**, President-Elect, Director of Policy, Center for Persons with Disabilities, Utah State University
- **Tawara Goode**, At-large member, UCEDD Director, Center for Child and Human Development, Georgetown University
- **Marc Tassé**, At-large member, UCEDD Director, Nisonger Center, The Ohio State University
- **Jack Brandt**, Council on Leadership in Advocacy Co-Chair, Disability Policy Specialist, Partnership for People with Disabilities, Virginia Commonwealth University
- **Angela Martin**, Council on Leadership in Advocacy Co-Chair, Sr. Associate Director for Community Supports and Services, Michigan Developmental Disabilities Institute, Wayne State University
- **Derrick Willis**, Multicultural Council Chair, Associate UCEDD Director, Center for Disabilities, University of Iowa
Location: Ronald Reagan Bldg. and International Trade Center, 6-10pm
(6-7p reception and networking, 7-8p program, 8-10p dessert and dancing)

Transportation to Gala – meet at entrance of The Madison Hotel
5:15pm – First coach bus boards directly in front of The Madison Hotel (ADA accessible)
6:00pm – Second bus boards directly in front of The Madison Hotel (ADA accessible)

Transportation back to The Madison Hotel – meet AUCD Guide in blue vest at gala registration table to be escorted to the 14th Street entrance (announcements will be made at the Gala for bus returns)
8:15pm – First bus boards to leave Gala and return to The Madison Hotel (ADA accessible, 55 passenger)
9:00pm – Second bus boards to leave Gala and return to The Madison Hotel (same bus)
10:00pm – Final bus boards to leave Gala and return to The Madison Hotel (same bus)
<table>
<thead>
<tr>
<th>Bus</th>
<th>Departure Location</th>
<th>Departure Time</th>
<th>Arrival Location</th>
<th>Arrival Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coach Bus</td>
<td>The Madison Hotel-directly outside of the Main Lobby doors</td>
<td>5:15 PM &amp; 6:00 PM</td>
<td>Ronald Reagan Building and International Trade Center</td>
<td>5:35 PM &amp; 6:20 PM</td>
</tr>
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AUCD Staff contact:
Danielle Johnson
240-316-6333
Thank you

Enjoy refreshments, and enjoy the gala

Tomorrow breakfast starts at 7:30 am, meeting starts at 9:00 am