

Joint UCEDD/LEND Directors Meeting

November 11, 2018





AUCD Board Governance

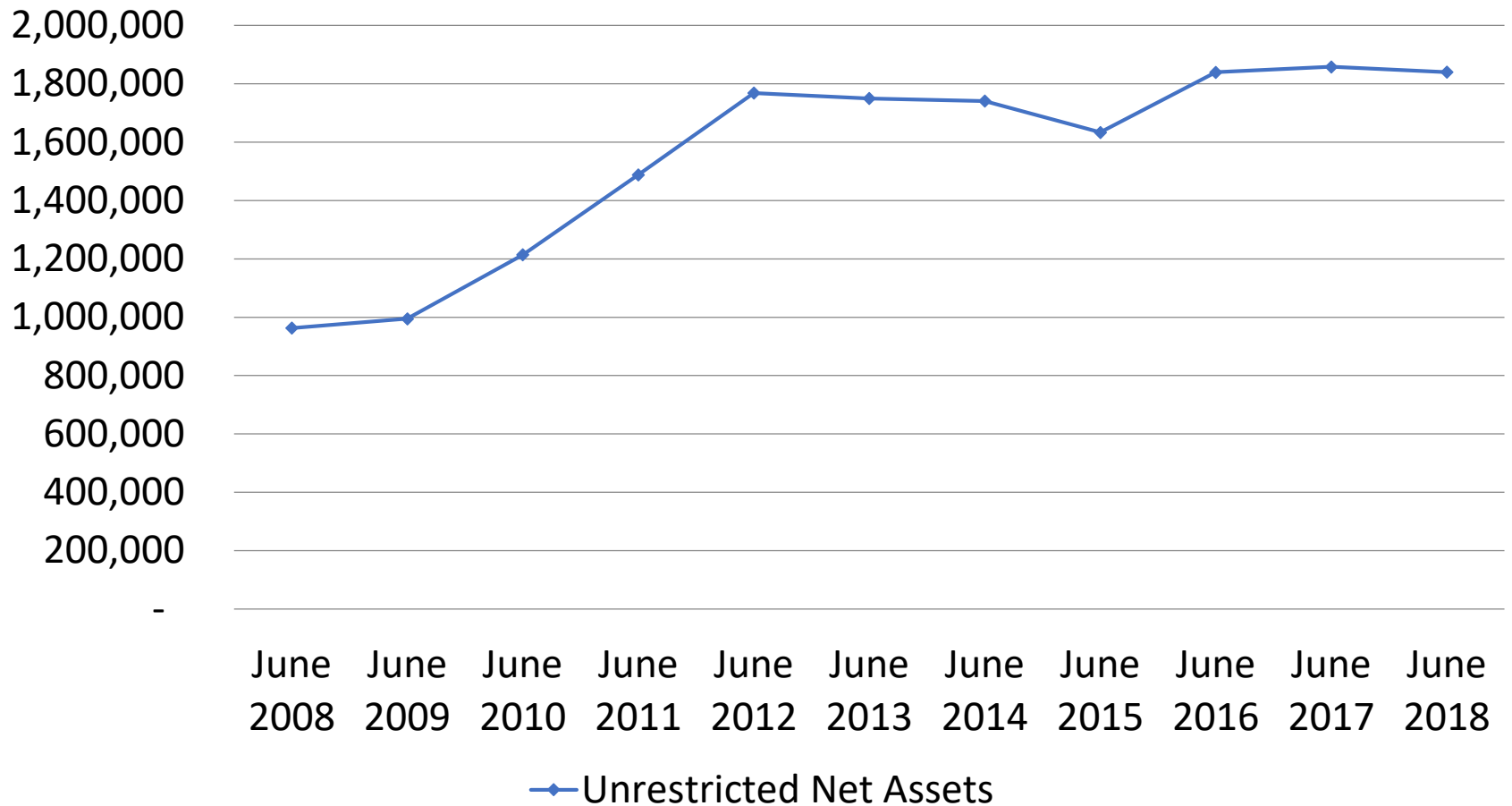
- 2014: Added MCC Co-Chair and broadened eligibility criteria for at-large positions beyond Director/Associate
- Significantly increased racial and ethnic diversity of Board nominees and members in 4 years
- 2017: IDDRC directors eligible to vote and run in Board elections; eliminated past-past president
- 2019: Board will ask members for vote on by-laws:
 - Combining Secretary-Treasurer positions
 - Removing MCC Co-Chair
 - Authorizing Board to create (and phase out, where appropriate) up to 4 additional at-large seats on Board to increase representation for specific constituencies

Financial Year Highlights

- AUCD received a clean audit opinion for the annual and OMB Uniform Guidance audits for the financial year ending on June 30, 2018.
- Year-end unrestricted net assets were \$1,839,660 which is \$18,300 less than the prior year.
- AUCD passed to its members \$2.5 million in funding compared to \$1.2 million of funding in the previous year.
- There have been no dues increases over the past three years.

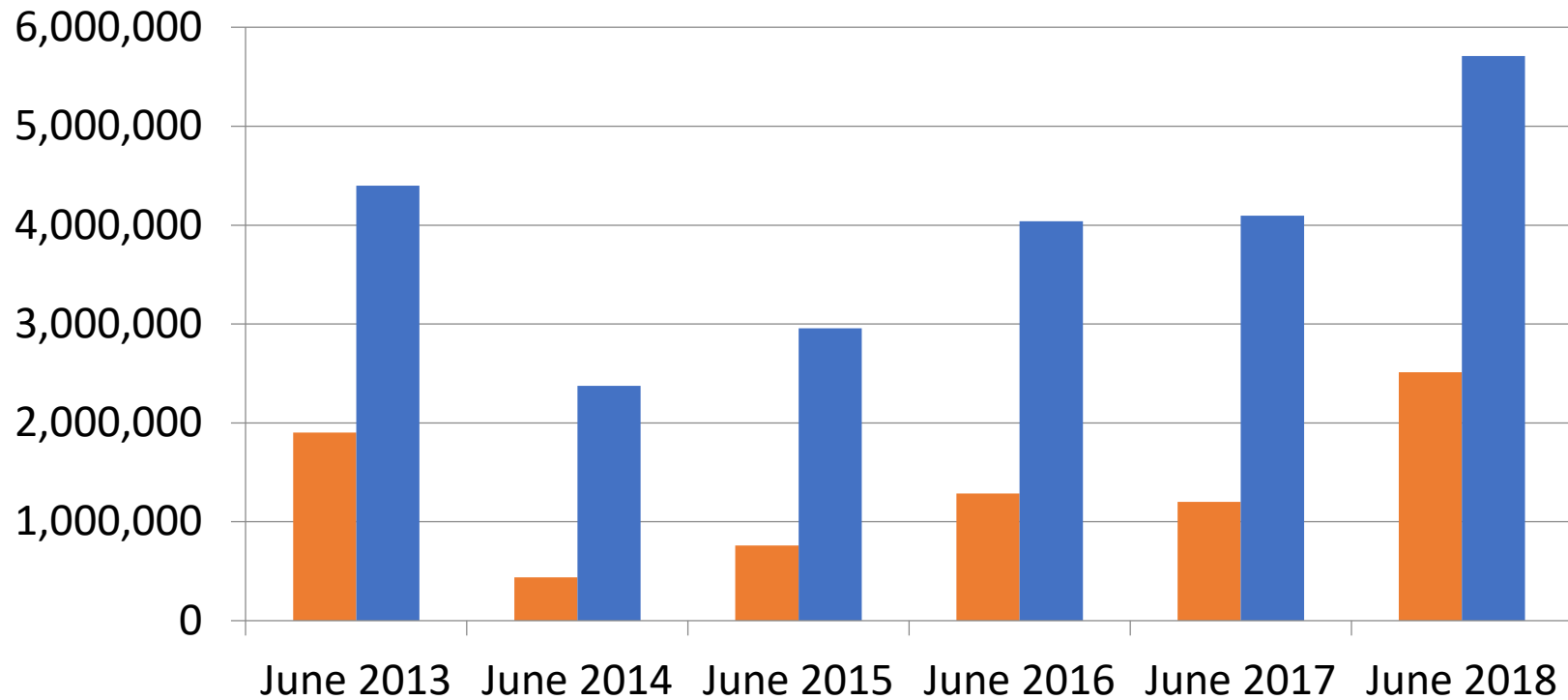


Multi-Year Unrestricted Net Assets



Funding Passed to Membership

- Funding passed to Membership
- Grants/Contracts



AUCD – New Staff



Natalie Martinez
Data Support Manager



Luis Valdez, MPH
Program Specialist



Rylin Rodgers
Director of Public Policy



Troy Washington, MPA, JD
Director of Finance & Grants Administration

AUCD – New Board Members

Jacy Farkas, MA
Training Director
Sonoran UCEDD (AZ)
Co-Chair, MCC



Ronda Jenson, PhD
Research Director
Institute for Human Development (AZ)
Chair, CORE

Eileen McGrath, PhD
Associate Director
AZLEND
Chair, NTDC



Scott Pomeroy, MD, PhD
Director
Childrens' Hospital Boston IDDRC (MA)
At-Large Member

AUCD **LEADERSHIP** **ACADEMY**

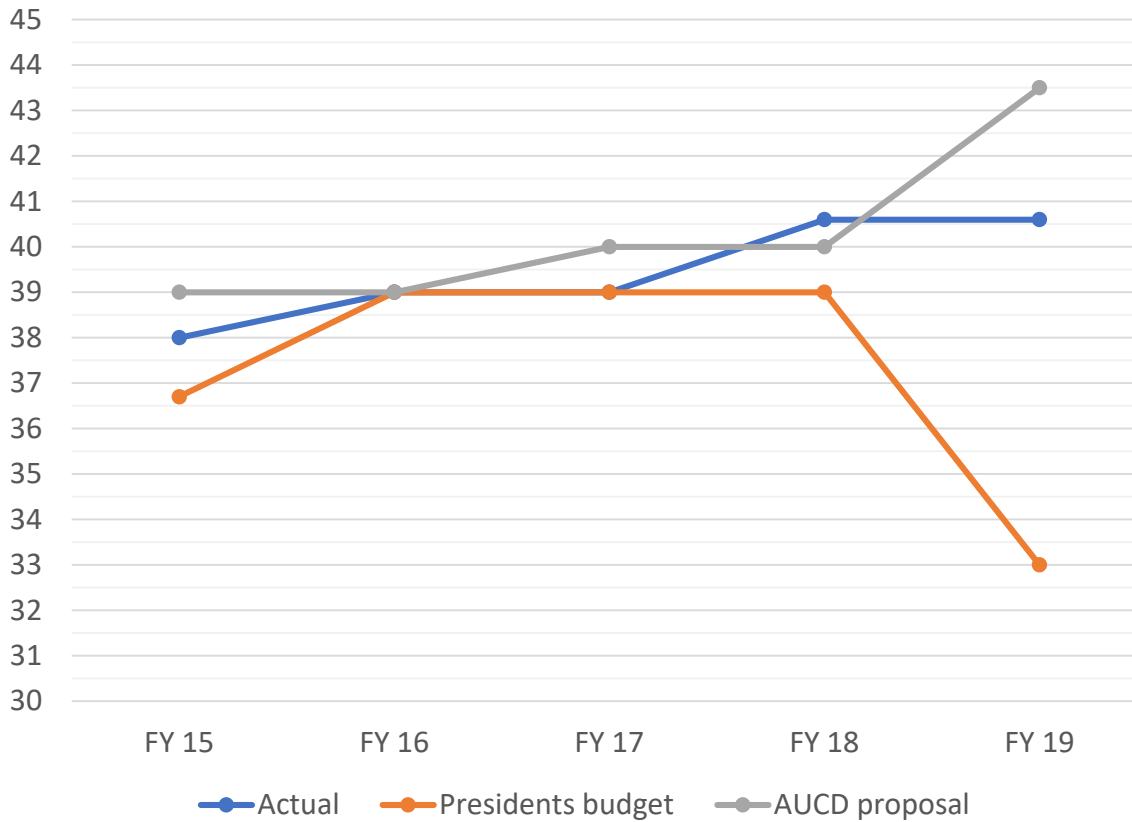
Shaping the future of disability



Applications due March 1, 2019
Notifications by March 31, 2019
Academy in Atlanta June 23-28, 2019

UCEDD Appropriations

History

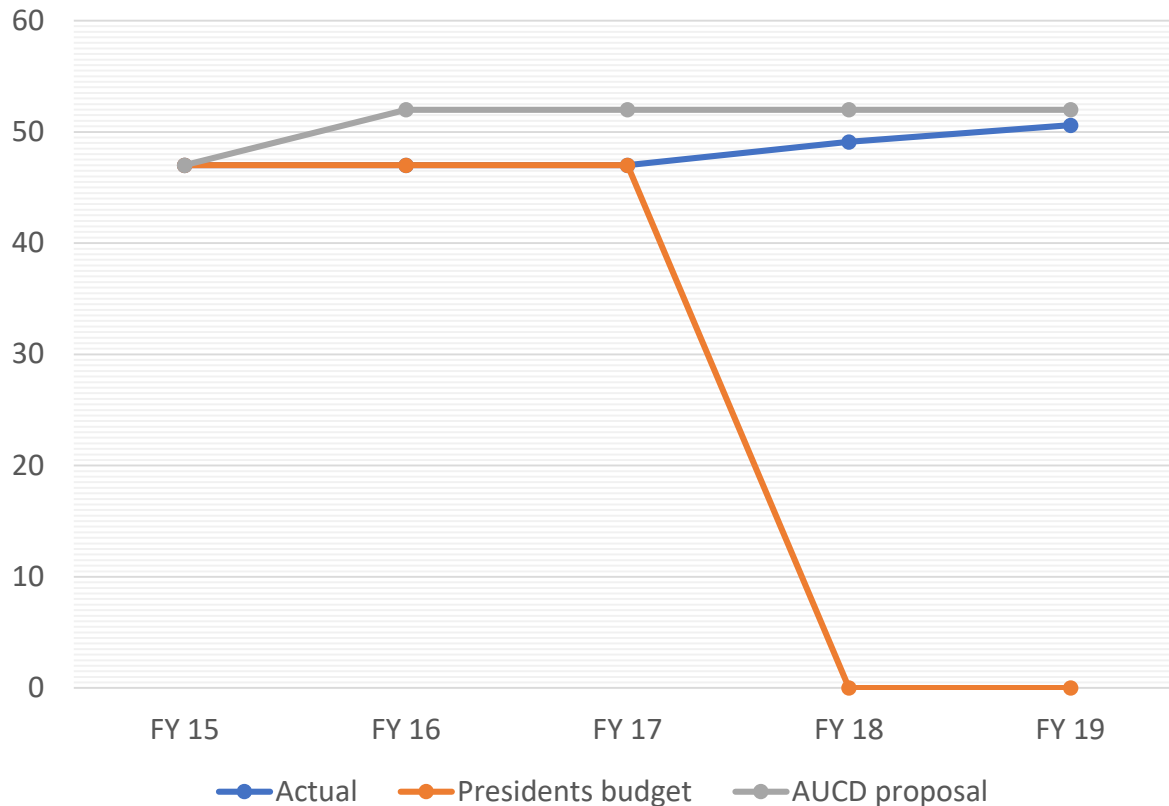


FY 20

Presi- dent's FY 20 Proposal	AUCD's FY 20 Request
TBD	\$43.5

LEND Appropriations (Autism and other DD)

History



FY 20

Presi- dent's FY 20 Proposal	AUCD's FY 20 Request
TBD	\$52

Federal Partner Discussion

Georgina Peacock, MD, MPH, FAAP

Director, Division of Human Development
and Disability, NCBDDD/CDC



Lisa Kaeser, JD

Director, Office of Legislation
and Public Policy, NICHD/NIH



Eunice Kennedy Shriver National Institute
of Child Health and Human Development
Health research throughout the lifespan

Laura Kavanaugh, MPP

Deputy Associate Administrator for
Maternal and Child Health, MCHB/HRSA



Updates from CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD)

Georgina Peacock, MD, MPH, FAAP

Presentation to UCEDD/LEND Directors
November 11, 2018







**SAVING
BABIES**



**HELPING
CHILDREN**



**PROTECTING
PEOPLE**



**IMPROVING
HEALTH**

Thematic Areas

- **Mothers and Babies:** Continue to maintain and adapt multi-pronged surveillance approach to rapidly respond to health threats to mothers and babies
- **Ready to Learn:** Support a healthy launch into school for at-risk children through early screening, identification and intervention for developmental disabilities
- **Transition of Care:** Implement nationwide transition readiness programs to promote successful transitions from pediatric to adult healthcare for adolescents with disabilities/disorders



Updates

- Zika Vital Signs – August 2018
- Zika Pregnancy and Infant Surveillance System adapting to monitor health threats
- Infants outcomes related to opioids



Updates

- *Pediatrics* supplement on Duchenne Muscular Dystrophy published
 - 13 articles and toolkit
- Autism
 - Funding announcement for ADDM Network
 - Developing website with interactive state-level data



**HELPING
CHILDREN**

Updates

- Hemophilia – used Community Counts data to determine causes of poor patient outcomes and educate HTC's
- Sickle Cell – published numerous stories highlighting the lives of sickle cell patients



PROTECTING PEOPLE

Improving Health

- Recent MMWR using 2016 BRFSS data
 - 1 in 4 adults (61 million) in U.S. with at least of the disabilities
- BRFSS guide published for use by BRFSS state coordinators and researchers interested in monitoring disability
- Spina Bifida Clinical Care Guidance published
- Transition from pediatric to adult health care



IMPROVING HEALTH



Thank you!

For more information, contact CDC
1-800-CDC-INFO (232-4636)
TTY: 1-888-232-6348 www.cdc.gov

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.



BREAK

Concurrent UCEDD, LEND meetings start at 4:45 pm

UCEDD Directors	LEND Directors
Stay here Grand Ballroom South/Central	Across back hall Congressional A/B

Coffee break is in this room only, so LEND folks be sure to get yours before heading across the hall!



UCEDD Directors Meeting

November 11, 2018



Welcome New UCEDD Directors



Rebekah Young, PhD

Mississippi

Maureen Van Stone, Esq., MS

Maryland (interim)



Jesse Suter, PhD

Vermont

George Gotto, PhD

Missouri (interim)



Amy Hewitt, PhD

Minnesota

Kudos to Retired UCEDD Directors

- Carl Calkins, PhD (MO)
- Leslie Cohen, JD (AZ-Sonoran)
- Chris Smith, PhD (MD)
- David Johnson (MN)
- Bill Kiernan (MA)
- Karen Edwards (NY-Westchester)



UCEDD Performance Measures

- New 5-year reporting measures require approval by White House Office of Management and Budget (OMB)
 - Implementation pending OMB approval
- AIDD has requested OMB approval to change follow-up trainee survey data to be collected at 2, 5, and 10-year intervals
 - Implementation pending OMB approval
- DICLC performance measures



What's new in AUCD's *Diversity & Inclusion Toolkit*



- Responsive menu and easier navigation
- Resources no longer separated by audience
- Redesigned & improved search function
- Greater emphasis on case studies
 - Success stories on network initiatives to enhance diversity, inclusion, and cultural and linguistic competence
 - Anyone may submit a story through the website

AUCD Emerging Leaders Community



**AUCD Emerging Leaders
Community**

- A diverse community of Trainees and Early Career Professionals dedicated to making a difference for people with disabilities throughout the world.
- Learn, connect, get involved, and grow with us!

www.aucd.org/EmergingLeaders



Research Roundup

- Vision: *A dissemination mechanism to highlight AUCD network research in an accessible and inclusive format*
- Seeking Steering Committee members
 - The steering committee will provide support, guidance, and oversight to AUCD staff working on the project.
 - Review and suggest solutions for the issues critical to project success (identifying key stakeholders, appropriate literacy level, project relevance, etc.).
- lvaldez@aucd.org by November 30

Leadership Transition Resources



- Support new leaders in navigating the challenges of leadership through organizational transition & change
- Subcontract to Matthew Williams, Principal, Liberating Leadership, LLC
 - Focus group of 6 newer Directors; survey of all Directors
 - Initial question for your feedback:
What is one piece of advice for incoming UCEDD Directors?
 - Analyze findings and draft resources to test with focus group
 - Final resources workshopped at 2019 UCEDD TA Institute



UCEDD Promotion Tools

- To help UCEDDs develop messaging that promotes their purpose and value within the university
- Tools will guide development of:
 - UCEDD elevator speech
 - Messaging about UCEDD's role, value and contribution to University across various priority areas
- Future tools planned:
 - Improved Directory to identify network expertise
 - Data & infographics representing UCEDD impact



Coffee & TA on UCEDD Core Functions

- Eight-part series of webinars and tip sheets on:
 - UCEDD core functions as they are categorized in NIRS
 - Planning and integrating core functions
- Lasting resources to help UCEDD leadership train new team members
- Completed:
 - Interdisciplinary pre-service preparation
 - Continuing education



Neonatal Abstinence Syndrome NTI

- Purpose: Identify and train practitioners in current and emerging knowledge and evidence-based and promising practices in screening, monitoring and care for children diagnosed with NAS, or suspected of being impacted by opioid use disorder and related trauma exposure
- Activities: Develop & test curriculum and interdisciplinary training model; provide recommendations for future funding to AIDD, CDC, MCHB, SAMHSA
- Awardee: Wyoming Institute for Disabilities partnering with Nisonger Center and UCinn UCEDD



URC Evaluation

- Evaluation designed by Mathematica in 2017 to:
 - Document TA services provided
 - Aid in continuously improving TA
 - Standardize data collection
- First year of data collection completed 2017-2018
- Final report near completion, addressing:
 - TA activities, products, events, collaborations
 - Quality of TA
 - UCEDD participation in & satisfaction with TA
 - Trends, limitations, achievements, lessons learned, goals



Commissioner's Address

Julie Hocker, MBA, Commissioner

Administration on Disabilities

Administration on Community Living





Roundtable Discussions

1. How to recruit and meaningfully involve affiliated faculty
2. Knowledge translation and marketing, and the difference between them
3. UCEDD core funds: use in addressing emerging issues & program dev't
4. Administrative and organizational tools that facilitate smooth operations
5. Transitioning to a responsibility center budget management model
6. Succession planning: addressing gaps in the pipeline, and retaining Associate Directors who may be recruited for vacant Director positions
7. Protecting the integrity of the UCEDD within the host University
8. Partnering with Minority-Serving Institutions
9. Embedding Cultural Diversity and Cultural and Linguistic Competence: resources and tools to support UCEDDs in their journey
10. TA Tool: Messaging to Promote UCEDDs within University



Conference Welcome Reception

Join the fun in the Renaissance Ballroom

