# Navigating the Crossroads: Federal Policy and the Future of Disability Services

Approaching a historical presidential election and navigating the narrow margins of a divided Congress



#### **Nice to Meet You!**



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#### **Our Team**



Elise Aguilar



Noah Block



Lydia Dawson



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André Floyd



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Donna Martin



Barbara Merrill



Lauren Middleberg



Mariana Nork



**Cindy Ramos** 



Tom Rice



Gabrielle Sedor



Sasha Sencer



Alli Strong-Martin



Robyn Wolfe



### **Our Purpose**

# Advancing the future of supports and services for people with intellectual and developmental disabilities



### **ANCOR** by the Numbers



2,500+
private providers
of I/DD services

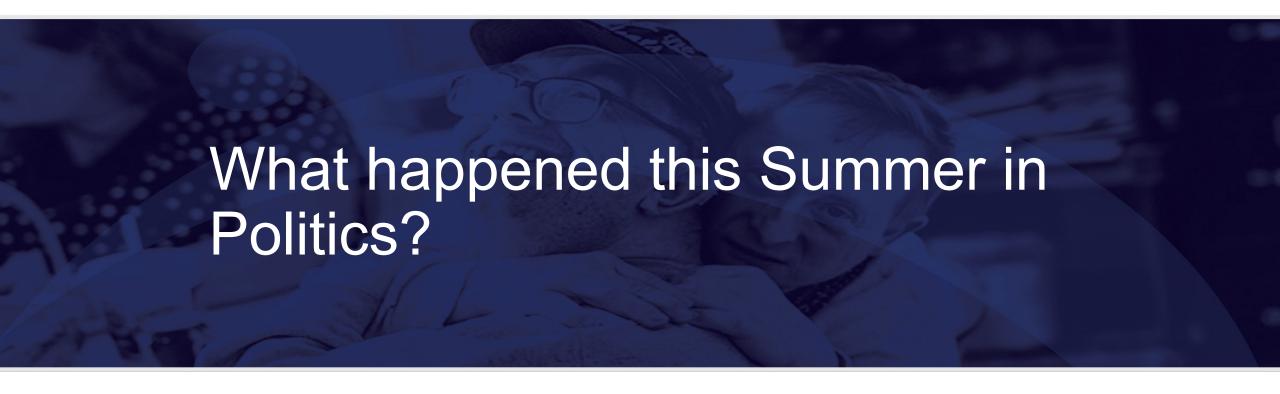


**61** state provider associations



15 100% state associations





















### Moral of the story?

The universe will punish you if you leave your house.



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The universe will punish you if you leave your house.

The only constant, especially in Washington, is change.



### Election 2024: What are the Major Dynamics to Watch?



We're in uncharted waters in an **unprecedented election** 



The strength of Democratic candidate performance in traditionally Republican states (Ohio, Montana, Texas)



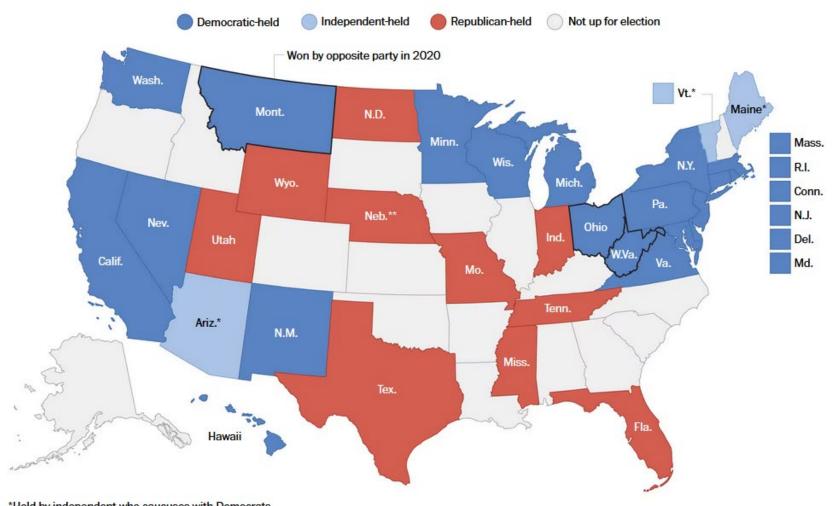
Turnout and composition of voters in Harris-Trump election will impact downballot races. **but by how much?** 

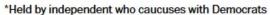


Control of the House will largely be determined by California and **New York** 



### **2024 Senate Races**

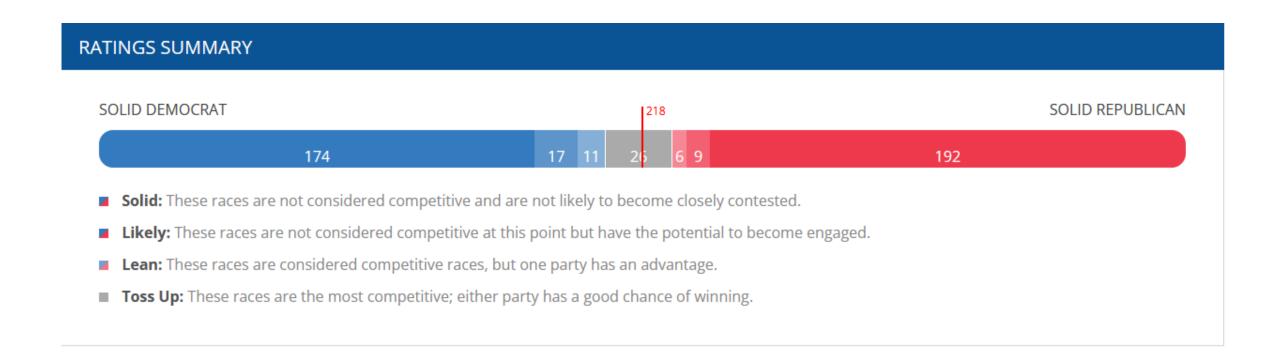




<sup>\*\*</sup>Regular and special election



### State of the House Races: 43 Tossup or Lean Seats

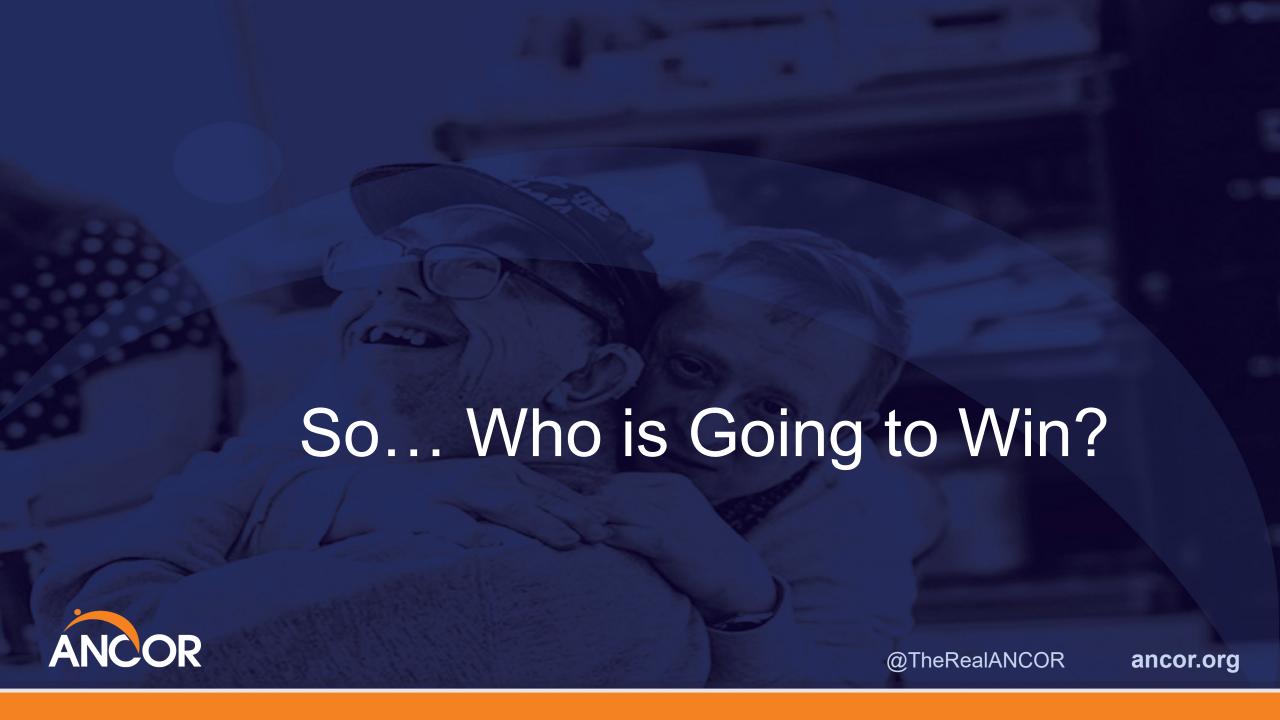




### 7 Seats are in New York

LIKELY DEMOCRAT	LEAN DEMOCRAT	DEMOCRAT TOSS UP	REPUBLICAN TOSS UP	LEAN REPUBLICAN	LIKELY REPUBLICAN
16 Dem • 1 Rep	10 Dem • 1 Rep	12 Dem • 0 Rep	0 Dem • 14 Rep	0 Dem • 6 Rep	0 Dem • 9 Rep
0 Ind	0 Ind	0 Ind	0 Ind	0 Ind	0 Ind
AL-02 NEW SEAT  CA-09 Harder  FL-09 Soto  IL-17 Sorensen  IN-01 Mrvan  KS-03 Davids  MD-06 OPEN (Trone)  MI-03 Scholten  NH-01 Pappas  NH-02 OPEN (Kuster)  NV-01 Titus  NV-04 Horsford  NY-03 Suozzi  OH-01 Landsman  OR-04 Hoyle  TX-28 Cuellar  WA-08 Schrier	CA-47 OPEN (Porter) CA-49 Levin CT-05 Hayes MN-02 Craig NV-03 Lee NY-18 Ryan NY-22 Williams OH-09 Kaptur OR-06 Salinas PA-17 Deluzio TX-34 Gonzalez	AK-AL Peltola CO-08 Caraveo ME-02 Golden MI-07 OPEN (Slotkin) MI-08 OPEN (Kildee) NC-01 Davis NM-02 Vasquez OH-13 Sykes PA-07 Wild PA-08 Cartwright VA-07 OPEN (Spanberger) WA-03 Perez	AZ-01 Schweikert  AZ-06 Ciscomani  CA-13 Duarte  CA-22 Valadao  CA-27 Garcia  CA-41 Calvert  CA-45 Steel  IA-01 Miller-Meeks  IA-03 Nunn  NE-02 Bacon  NY-04 D'Esposito  NY-17 Lawler  NY-19 Molinaro  OR-05 Chavez-DeRemer	MI-10 James MT-01 Zinke NJ-07 Kean Jr.  PA-10 Perry VA-02 Kiggans WI-03 Van Orden	CA-03 Kiley CA-40 Kim CO-03 OPEN (Boebert) FL-13 Luna FL-27 Salazar NY-01 LaLota PA-01 Fitzpatrick TX-15 De La Cruz WI-01 Steil





### ANCOR's Approach to Steadying the Ship

**Advocate for Beneficiary Rights and Protections** 

Improve Medicaid-Funded
I/DD Services Infrastructure

Strength the Direct Support Workforce



### **Taking in the Bigger Picture**

- State and federal policies are often interwoven.
- Medicaid is a federal-state partnership.
- At the federal level Congress sets federal funding for Medicaid, while CMS sets the rules and provides guidance / oversight.
- States implement programs and funds at the matching rate set by a formula.
- States regularly change policies in reaction to federal policy developments.





### **Recent Accomplishments**

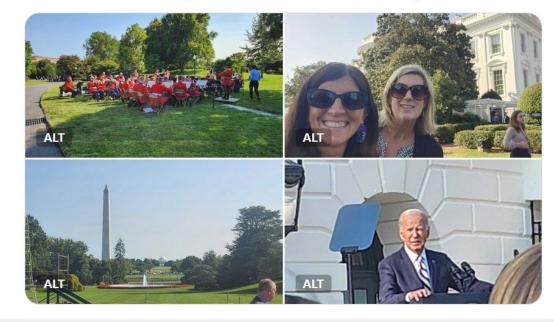
- \$150 billion in proposed funding in President Biden's FY 2025 budget proposal
- President Biden's Executive Order on caregiving
- Acknowledgment of care workers in President's 2024 State of the Union Address
- Establishment of National Care Workers Recognition Month
- Acknowledgment of recruitment and retention challenges in administrative rulemaking
- \$37 billion in federal ARPA spending on workforce initiatives
- Unanimous Senate and House Committee passage of Recognizing the Role of Direct Support Professionals Act ("the SOC bill")







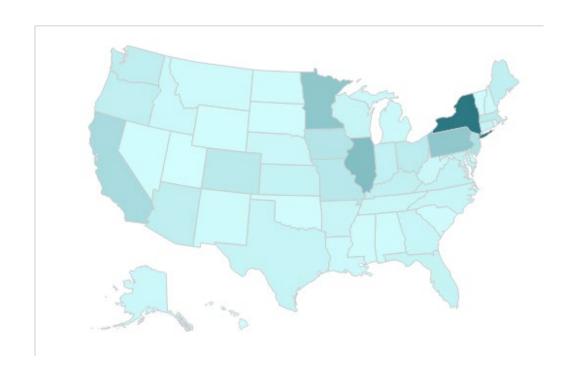
Gabrielle Sedor, ANCOR COO & Foundation Director, at the White House celebration of Disability Pride Month & ADA Anniversary!







### Year in Review: New York's Advocacy



### 6,000+

The number of messages sent by New York advocates in the last year

### 1,060

The number of New York advocates taking action in the last year

### 1st!

New York ranking among all states



ANCOR

## ANCOR Amplifier



Write your members of Congress. Share resources with legislative staff. Make your voice heard. All of these are great ways to support more inclusive communities.







**Call on Your Representative** to Recognize Direct Support **Professionals** 

**DOL Overtime Rule Action** Center

Advocate for the HCBS Relief **Act: Strengthen Community** Services

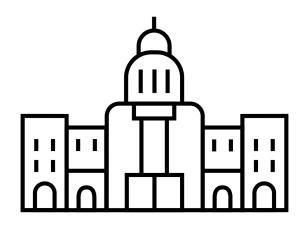
### Advocacy Toolkit



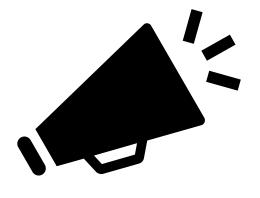
### ancor.org/advocacy/toolkit



### **Leadership through Committee Service**



Government Relations Committee



**Grassroots Committee** 



Housing Task Force



### **Regulatory Activity**

- Access Rule
- Overtime Rule
- 504 Regulations
- Adult Protective Services Regulations
- Streamlining Eligibility & Renewal Rule

- Workplace Violence in Healthcare Settings
- Subminimum Wage
- Shock Ban
- FEMA Public Assistance Regulations
- ...and many more!



# The U.S. Rulemaking Process





Regulatory Drafting



Interagency Review





Agency Revisions



Interagency Review



Final Publication





## The U.S. Rulemaking Process continued

Where we are with:

Subminimum Wage Rule (Employment of Workers With Disabilities Under Section 14(c) of the Fair Labor Standards Act





Agency Revisions



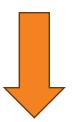
Interagency Review



Final Publication

#### Where we are with:

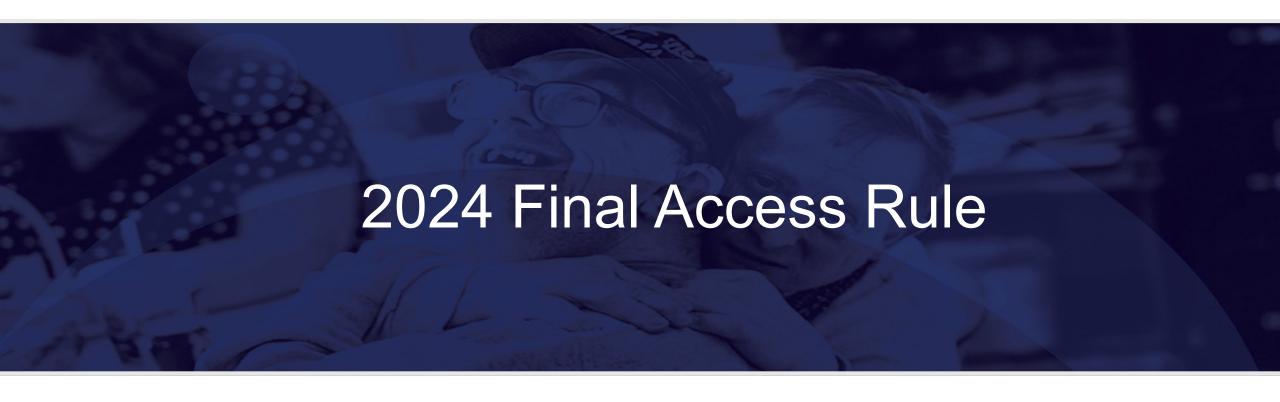
- Access Rule (Ensuring Access to Medicaid Services)
- Overtime Rule (Defining and Delimiting the Exemptions for Executive, Administrative, Professional, Outside Sales, and Computer Employees)





Congressional or Judicial Review







### **Ensuring Access to Medicaid Services**

The proposed access rule seeks to increase transparency and accountability, standardize data and monitoring, and create opportunities for States to promote active beneficiary engagement in their Medicaid programs, with the goal of improving access to care across fee-for-service, managed care, and home and community-based services. [1915(c), 1915(i-k), and indicated 1115 demonstration waivers]

Publication date: May 10, 2024



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### **Access Rule Toplines**

- Medicaid Advisory Committee and Beneficiary Advisor Council
- Person Centered-Planning and Grievances
- Incident Management System
- HCBS Payment Adequacy (commonly known as 80/20 rule)
- HCBS Quality Measure Set
- Access, Rates, and Waiting Lists
- Reporting and Website



### **HCBS Access Provisions:** Applicability Dates

2026

FFS grievance systems

2028

- HCBS Quality Measure Set reporting
- HCBS payment adequacy reporting

2030

 HCBS payment adequacy minimum performance level 2032

2027

- Incident management system
- Critical incident reporting and minimum performance level
- Person-centered planning reporting and minimum performance level
- Waiver waiting list reporting
- Access reporting
- HCBS payment adequacy reporting readiness
- Website transparency

2029

• Electronic incident management system

2031

We considered whether the proposed requirements at § 441.302(k)(3)(i) related to the percent of payments going to the direct care workforce should apply to other services, such as adult day health, habilitation, day treatment or other partial hospitalization services, psychosocial rehabilitation services, and clinic services for individuals with chronic mental illness. However, these services may have facility or other indirect costs for which we do not have adequate information to determine a minimum percent of the payment that should be spent on compensation for the direct care workforce. We request comment on whether the proposed requirements at § 441.302(k)(3)(i) related to the percent of payments going to the direct care workforce should apply to other services listed at § 440.180(b). In particular, in recognition of the importance of services provided to individuals with intellectual or developmental disabilities, we request comment on whether the proposed requirements at § 441.302(k)(3)(i) related to the percent of payments going to the direct care workforce should apply to residential habilitation services, day habilitation services, and home-based habilitation services.

#### **ANCOR Members Were Loud About the Access Rule**



996

Individual Comments from ANCOR Supporters

Representing 44.56% of all total comments. This does not include comments from ANCOR provider agencies and non-ANCOR members.





### **HCBS Payment Adequacy (2030)**

States must meet the following minimum performance level as applicable, calculated as the percentage of total payment (not including excluded costs) to a provider for <u>furnishing homemaker</u>, <u>home health aide</u>, <u>or personal care services</u>, as set forth at § 440.180(b)(2) through (4), represented by the provider's total <u>compensation</u> to direct care workers.

Other than exceptions], the State must ensure that each provider spends 80 percent of total payments the provider receives for services it furnishes [as described above] on total compensation for direct care workers who furnish [those services.]



### Well, What is Habilitation?

Habilitation is defined in federal statute, as a waiver benefit, as follows (SSA 1915(c)(5)):

#### Habilitation services

- A. Means services designed to assist individuals in acquiring, retaining, and improving the self-help, socialization, and adaptive skills necessary to reside successfully in home and community based settings; and
- B. Includes (except as provided in subparagraph (C)) prevocational, educational, and supported employment services; but
- C. Does not include [educational and vocational rehabilitation services]



### **CMS Acknowledges States Differ in Interpretation**

Response: We understand that States have service definitions for homemaker, home health aide, and personal care services that differ from the definition of homemaker, home health aide, and personal care services in the section 1915(c) waiver Technical Guide<sup>112</sup> and that States do not always use these terms consistently. However, codifying definitions of homemaker, home health aide, and personal care services would have broad implications for State's HCBS programs that would extend beyond the HCBS payment adequacy requirements in this final rule. We will provide additional subregulatory guidance and technical assistance to aid in implementation of the HCBS payment adequacy requirements and may consider addressing in future rulemaking.



### **HCBS Payment Adequacy (2030)**

States must meet the following minimum performance level as applicable, calculated as the percentage of total payment (not including excluded costs) to a provider for furnishing homemaker, home health aide, or personal care services, as set forth at § 440.180(b)(2) through (4), represented by the provider's total compensation to direct care workers.

Other than exceptions, the State must ensure that each provider spends 80 percent of total payments the provider receives for services it furnishes [as described above] on total compensation for direct care workers who furnish [those services.]



### **Direct Care Worker**

- Nurses
- Certified Nursing Assistant
- Direct Support Professional
- Personal care attendant
- Home Health Aide
- Other individuals who are paid to provide services to address activities of daily living [], including nurses and other staff providing clinical supervision.



### **Excluded costs**

- Costs of required trainings for direct care workers (such as costs for qualified trainers and training materials)
- Travel costs for direct care workers (such as mileage reimbursement or public transportation subsidies); and
- Costs of personal protective equipment for direct care workers









### Compensation

- Salary, wages, and other remuneration as defined by the Fair Labor Standards Act and implementing regulations;
- Benefits (such as health and dental benefits, life and disability insurance, paid leave, retirement, and tuition reimbursement); and
- The employer share of payroll taxes for direct care workers delivering services authorized under section 1915(c) of the Act.



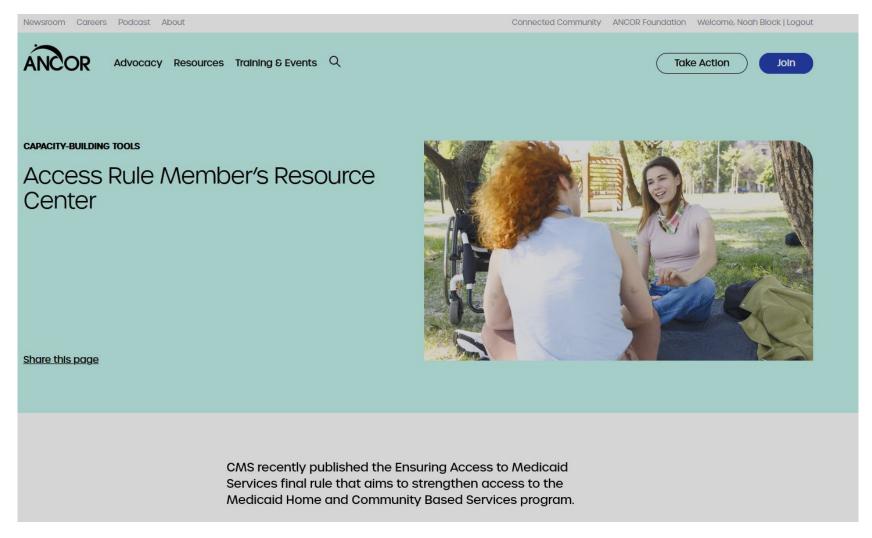
### **Exceptions**

At the State's option, for providers determined by the State to meet its State-defined small provider criteria, the State must ensure that each provider spends the percentage set by the State.

The State may develop reasonable, objective criteria through a transparent process to exempt from [HCBS Payment Adequacy] a reasonable number of providers determined by the State to be facing extraordinary circumstances that prevent compliance.



### **Explore the Members Only Access Rule Resource Center**





https://www.ancor.org/resources/access-rule/

### **ANCOR's Advocacy Continues**

- •We will work with the Administration to ensure sub-regulatory guidance is responsive and informed by challenges identified by providers.
- •We will work with ANCOR members, including our state associations, to develop resources and empower state-level advocacy for the rule's implementation.
- •We will continue to educate members of Congress and other federal policymakers about the impacts to community-based services for people with I/DD and the importance of ensuring payment rates are adequate to meet the rule and other new policy initiatives.
- •We will keep you up to date through the ACC and our action center.



# SEE YOU IN SAN DIEGO!

save the date

### **ANCOR CONNECT '25**

APRIL 7-9, 2025 SAN DIEGO, CA



### Thank you!



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