

# You Said UCEDD?: Policy, Advocacy, and the Developmental Disabilities Network

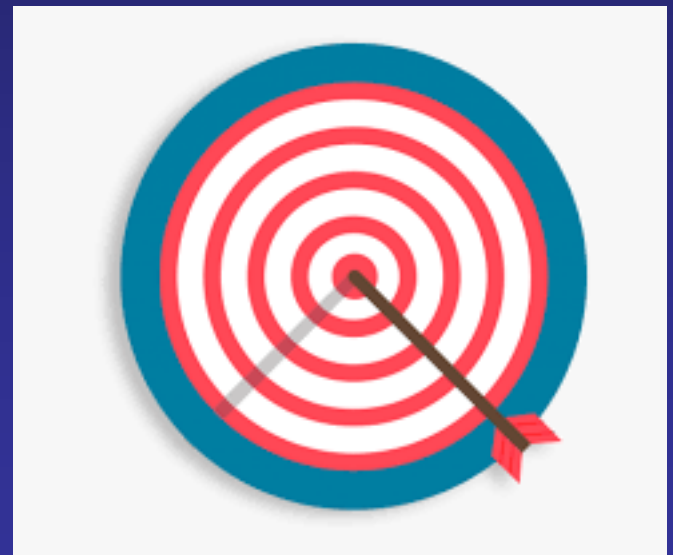
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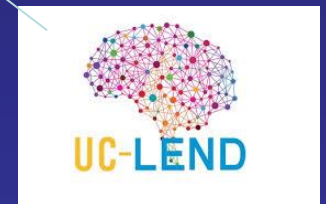
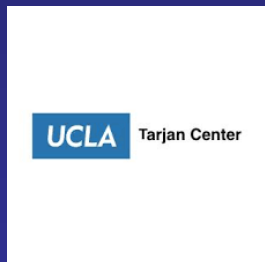
**UCLA** Tarjan Center UCEDD  
University Center for Excellence in  
Developmental Disabilities

# Objectives

- Understand the role of UCEDDs and other Developmental Disabilities (DD) Network Partners
- Identify strategies for disability policy and advocacy



# Association of University Centers on Disabilities (AUCD)



# LEND: Leadership Education in Neurodevelopmental and Related Disabilities

- **Who:** 60 programs in 44 states/territories. 4 in CA (UC-LEND, CHLA, UC Davis, UC San Diego/SDSU)
- **Funding:** Autism CARES Act
- **Administration:** Maternal Child Health Bureau (MCHB)
- **Role:** Interdisciplinary graduate-level training to clinicians, researchers, and community leaders on neurodevelopmental disabilities to improve care and outcomes across the lifespan



# IDDRC: Intellectual and Developmental Disabilities Research Center

- **Who:** 15 programs. 2 in CA (UCLA, UC-Davis)
- **Funding:** National Institute of Child Health and Human Development (NICHD)
- **Role:** Conduct research into the causes of intellectual/developmental disabilities. Evaluate the effectiveness of interventions. Training opportunities for researchers



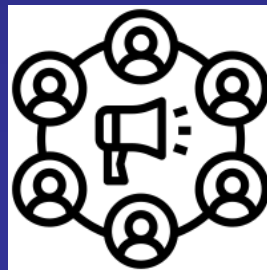
# UCEDD: University Centers for Excellence in Developmental Disabilities

- **Who:** 68 programs in every state/territory. 3 in CA (UCLA, UC-Davis, USC-CHLA).
- **Funding:** Authorized under DD Act
- **Administration:** Administration on Intellectual and Developmental Disabilities (AIDD)
- **Role:** Respond to state and local needs of people with disabilities through research, service, and education. Work to transform policies and systems. Member of the developmental disabilities (DD) network.

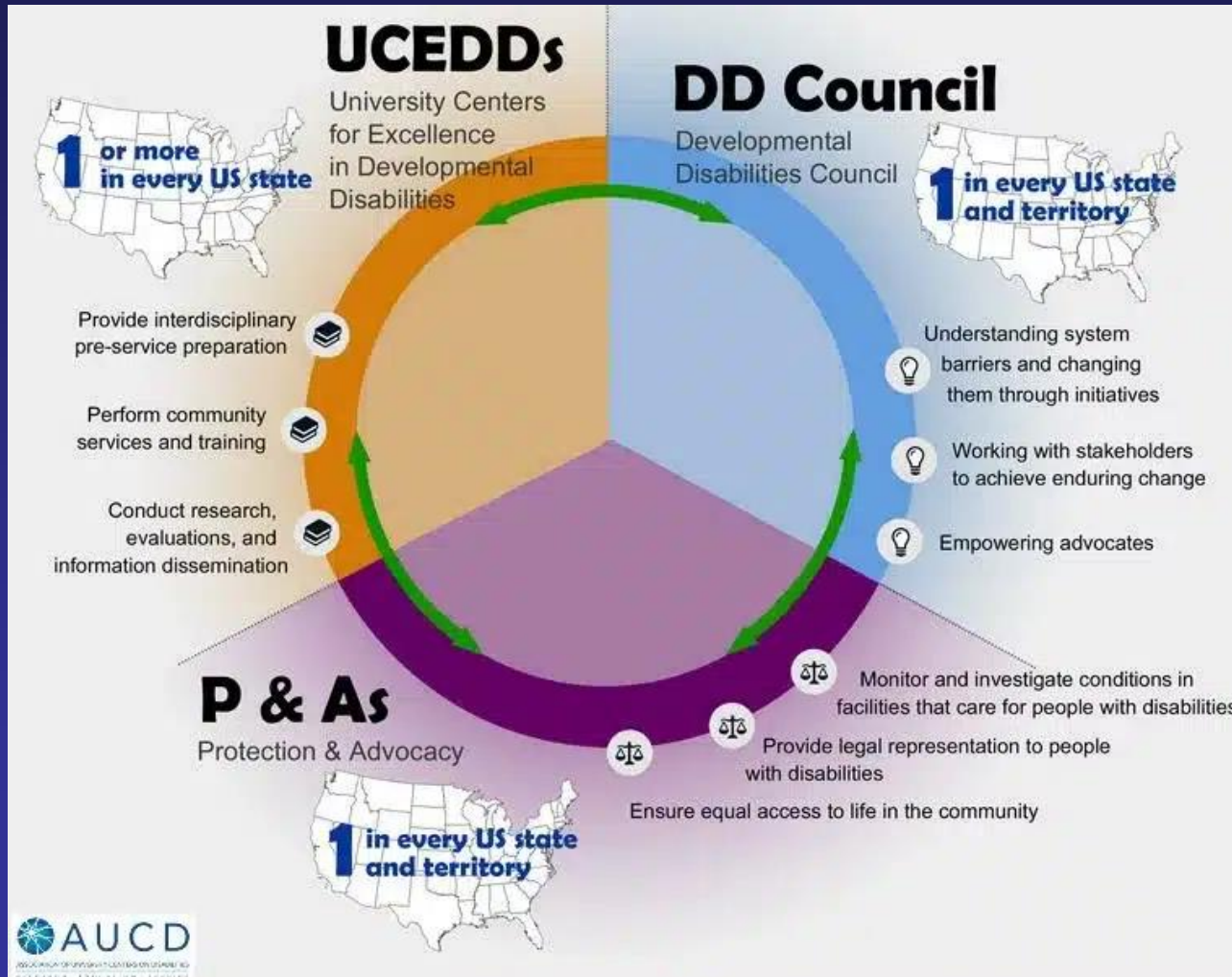


# UCEDD Core Functions

- **Research and Evaluation:** Researching and adding to the latest findings and policies.
- **Information Dissemination:** Providing useful information and resources
- **Interdisciplinary Training:** Training to professionals across disciplines
- **Community Service:** Understanding community training and technical assistance needs



# Developmental Disabilities (DD) Network





# State Council on Developmental Disabilities (SCDD)

- 31 members appointed by the Governor
- Members include individuals with disabilities, their families, federally funded partners and state agencies
- 5 year state plan
- Yearly work plan created by SCDD
- Yearly report to federal government



# Disability Rights California (DRC)

- 24 offices in CA with over 340 staff
- Protects and advocates for the rights of people with disabilities
- Advocacy through legislative action
- Legal aid services
- Training and outreach



# Advocates Can Offer 3 Things



**TIME**



**TALENT**



**TREASURE**

# Advocacy



# Personal Advocacy

- Speak on your **own** opinions
- Use your **own** email
- Use your **own** phone
- Use your **own** time
- Do not reference your employer



# Professional Advocacy

## Advocating/Educating

- Educate about what we know
- Educate about our experiences
- Cannot ask for specific bills/laws

## Lobbying

- Ask for specific bills/laws
- Done by registered (and paid) lobbyists
- Represent organizations/interests



# 5 W's of Communicating with Legislators: Who

- Know who your legislators are
- Look it up!
- Both state and federal representatives
- Staff



# 5 W's of Communicating with Legislators: What

- Know the message you want to give
- Use resources from organizations
- Search for bills on state and federal websites (end in .gov).





# 5 W's of Communicating with Legislators: Where

- State capitol
- Washington D.C.
- Virtually
- Community Events
- Local offices



# 5 W's of Communicating with Legislators: When

- Timing is everything
- Too soon and it's not on their radar
- Too late and it's too late



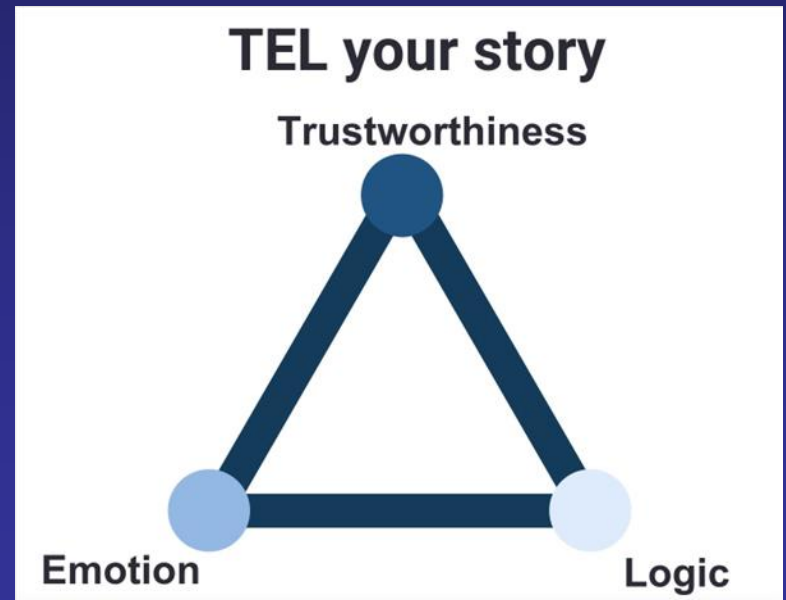
# 5 W's of Communicating with Legislators: How

- In person
- Virtually
- Email
- Phone call
- Use your time effectively!



# TEL Your Story

- UC Leadership Academy for Emerging Disability Rights Leaders
- 10 week virtual program
- Teaches advocacy skills
- TEL Your Story model



# TEL Your Story: Trustworthiness

- Build credibility
- Describe who we are
- What are my qualifications?
- Why am I an expert?



# TEL Your Story: Emotion

- Stories vs. numbers
- Talk about experiences
- Why does it matter to me?
- What is my story?



# TEL Your Story: Logic

- Back up your story
- Do your research
- Who does this impact?
- Do facts support my opinion?



# Remember

- Keep it short – under five minutes
- Advocacy is about relationships
- Strength in numbers





# Next Steps

- Work with AUCD members and DD Network partners
- Look up and contact your legislators
- Share your Time, Treasure, and Talents
- TEL your story
- **VOTE!**



# Questions

