

TEL Your Story: The UCLA Leadership Academy for Emerging Disability Rights Leaders

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Introductions

- Dr. Jasper Estabillo
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Agenda

- Background and needs assessment
- Collaboration strategies
- Pilot data
- Future directions

Learning Objectives

1. Understand individuals with lived experiences' *perspectives and priorities* about leadership curriculum
2. Learn *strategies for collaborating* with individuals with lived experience to create leadership curriculum
3. Describe *results* from pilot data of the Leadership Academy

**Why do we need a Leadership Academy
for individuals with disabilities?**

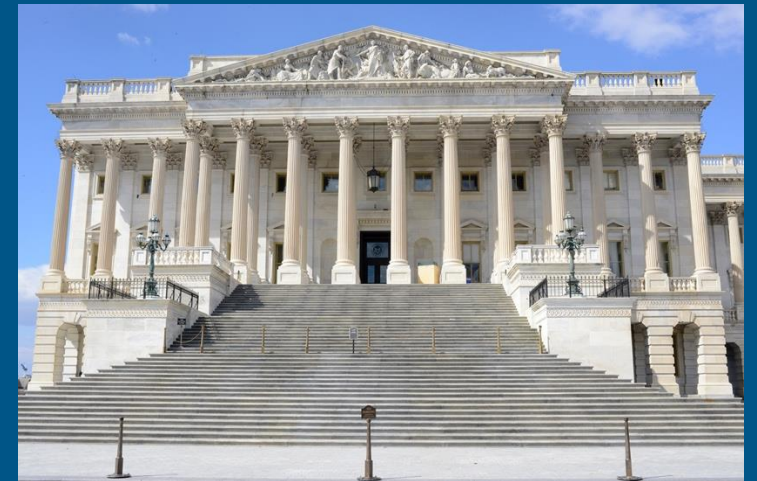
Background

- Progress in the disability rights movement is largely because of advocates with disabilities (lived experience)



Developmental Disabilities Assistance and Bill of Rights Act (DD Act)

- The DD Act is a federal law that makes sure that people with disabilities and their families:
 - Help design community services
 - Have access to services, supports, and assistance
- These services should promote:
 - Self-determination
 - Independence
 - Productivity
 - Integration
 - Inclusion
 - *In all parts of community life*



**Why do we need a Leadership Academy
for individuals with disabilities?**

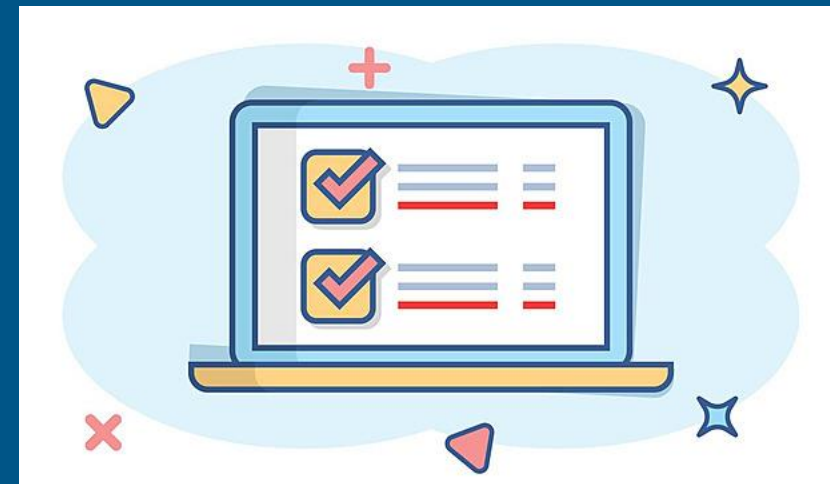
**To teach people with lived experience
how to advocate for themselves and
their communities!**

What should be taught in a Leadership Academy for individuals with disabilities?

What are the *perspectives and priorities* of individuals with lived experience?

Needs Assessment: Background

- Needs assessment with topics related to self-advocacy, disability policy, and employment was sent to CA state and community partners
 - Partners in Policymaking
 - Literature review
- Topics were rated 1-5, and then most and least important topics were selected
- Data were collected from April to July 2023



Needs Assessment: Demographics

- 88 Total respondents
- 28.4% identified as autistic



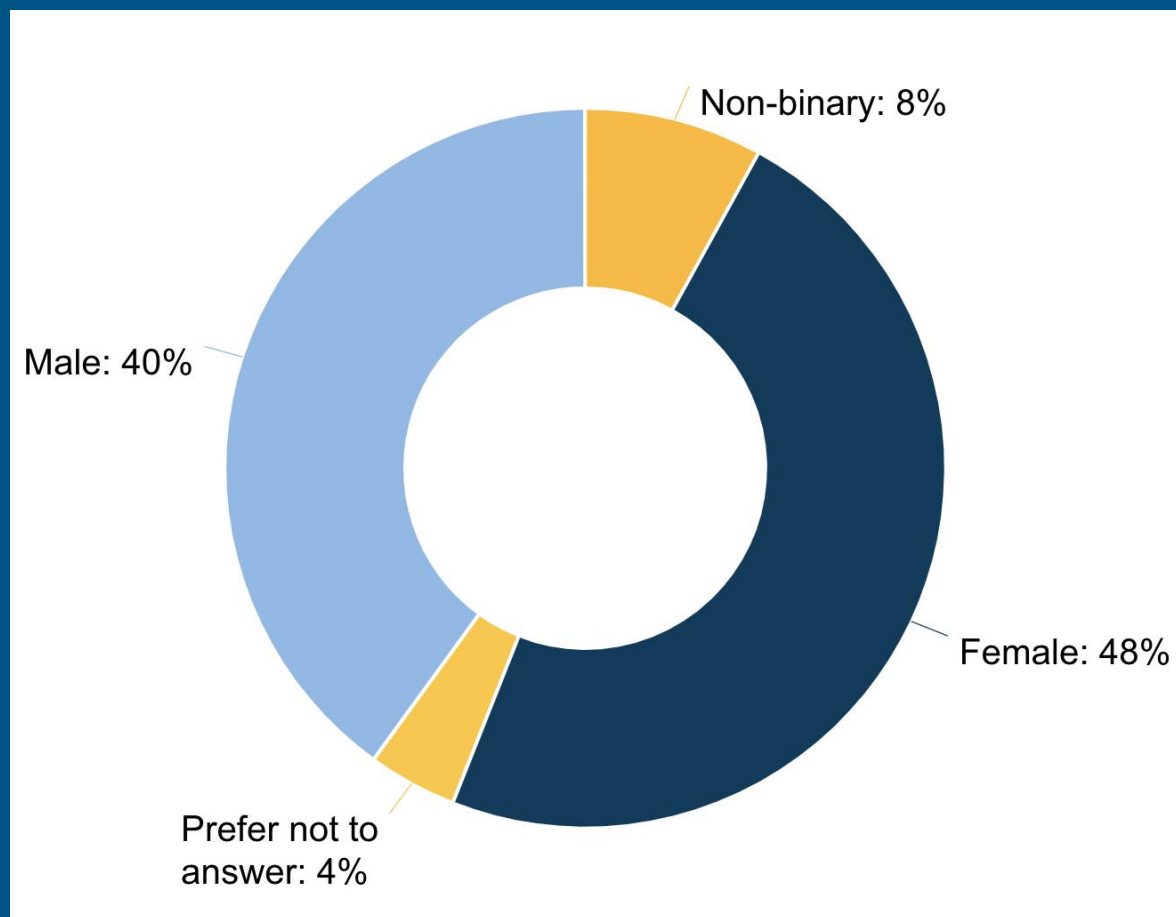
Mean = 30.35 years, *SD* = 7.84

Median = 28 years

Range: 19-54 years

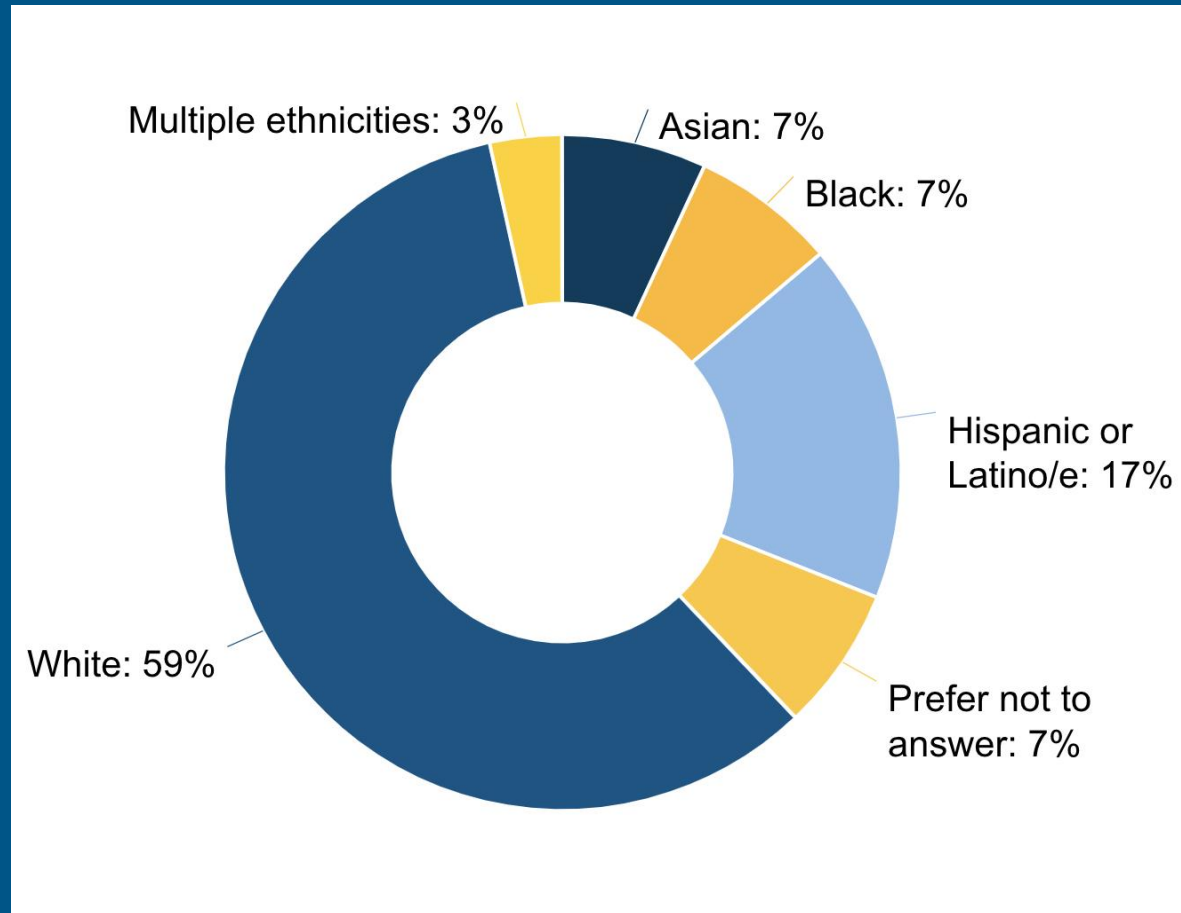
Needs Assessment: Demographics

- Gender:



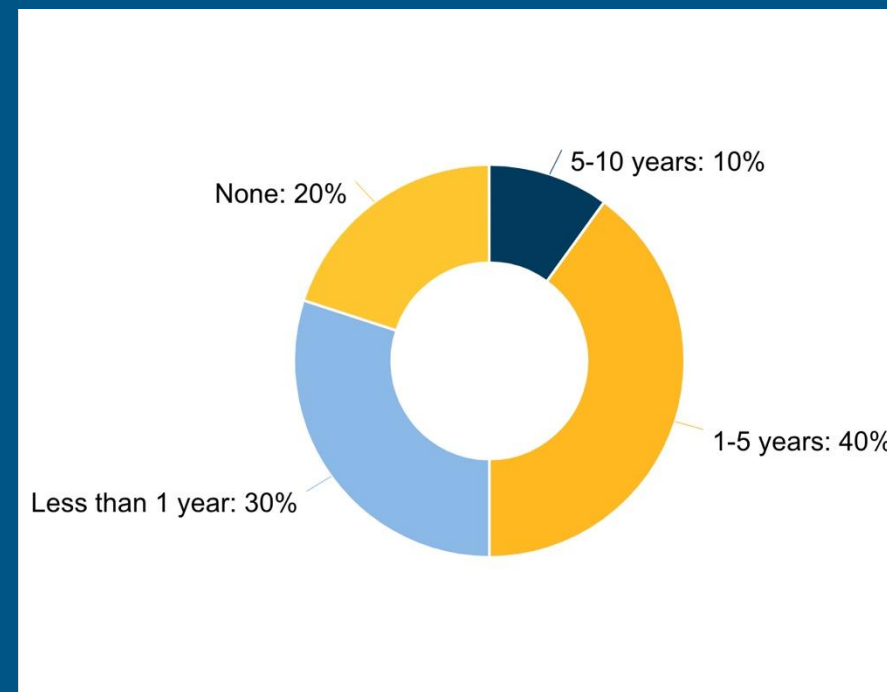
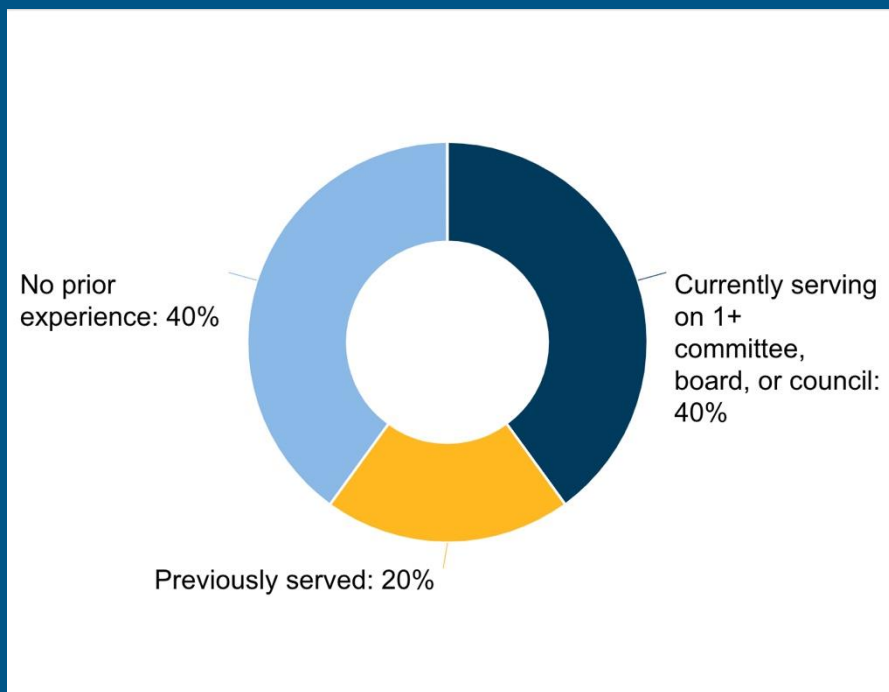
Needs Assessment: Demographics

- Race and ethnicity:



Needs Assessment: Demographics

- Advocacy experience:



Needs Assessment: Results

- Self-advocacy and disability policy topics all received high ratings (all $M \geq 4.0$)



Needs Assessment: Results



Needs Assessment: Conclusion

- Strong support for creation of a Leadership Academy
- Focus on *self-advocacy* and *understanding and making a change*
 - Knowledge and skills related to disability policy and advocacy

What should be taught in a Leadership Academy for individuals with disabilities?

What are the *perspectives and priorities* of individuals with lived experience?

Self-advocacy and understanding and making a change!

What are ways to include individuals with lived experience when making leadership curriculum?

Collaboration Strategies

- Involve individuals with lived experience from the *start*
- Include at *every* step of the process
- Prioritize *accessibility* and *inclusivity*
- *Value* and *compensate* contributions
- Gather and *act* on feedback

Collaborative Process

- Included partners with lived experience
 - Accessibility
 - Helped select speakers
 - Visuals
- Co-led sessions
 - Used topics from needs assessment
 - Used expertise and lived experience



What are ways to include individuals with lived experience when making training curriculum?

Before, during, and after (ALL THE TIME).

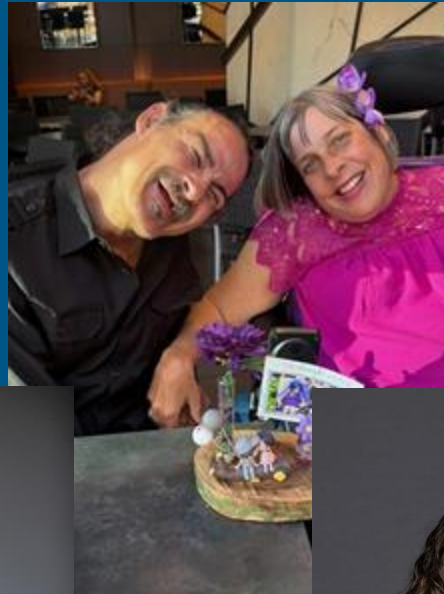
What is the UCLA Leadership Academy for Emerging Disability Rights Leaders?

Leadership Academy Curriculum

- 10-week program
- 2-hour sessions on Zoom each week
- Topics:
 - Disability History
 - Government
 - Advocacy Skills
 - Self-advocacy
 - Testifying
 - Storytelling
- Coaching and skills practice

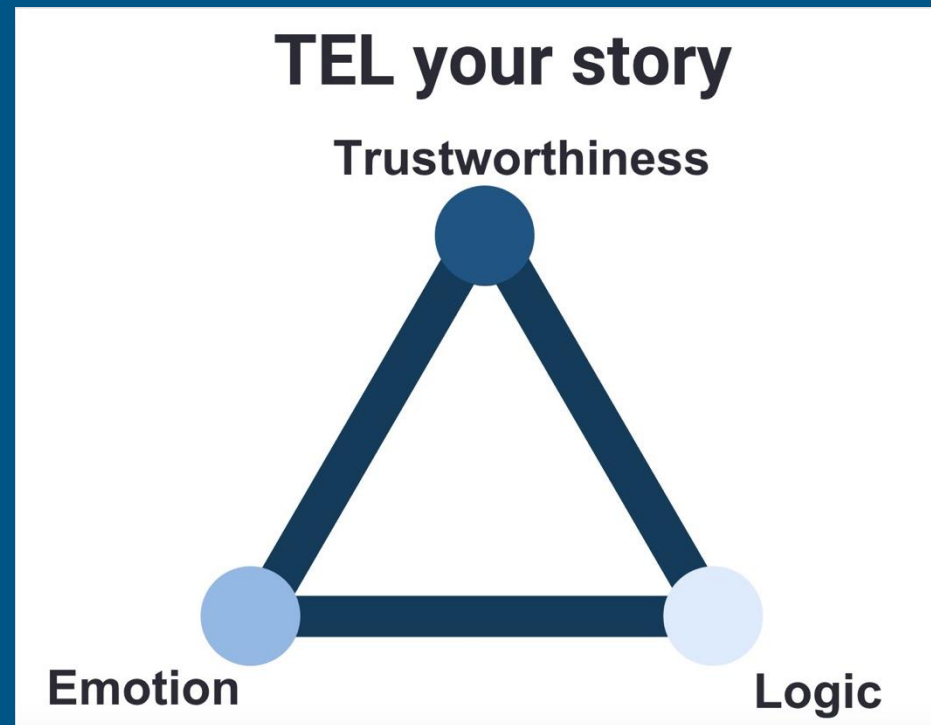


Leadership Academy Speakers



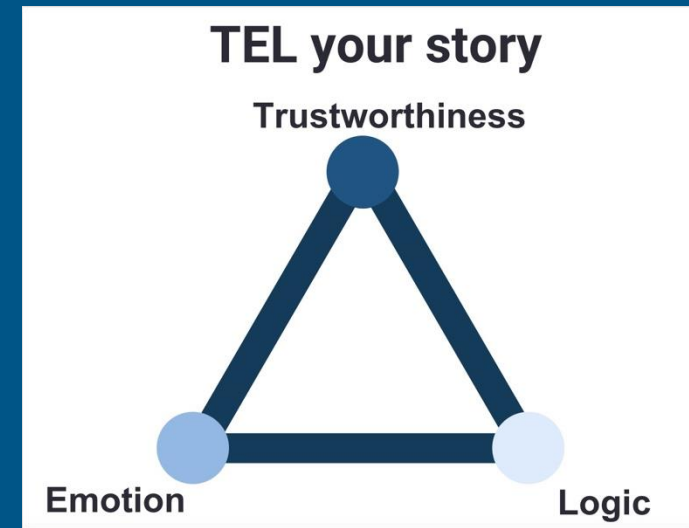
Leadership Academy Skills

- Introductions
- Advocacy
- “TEL” Your Story



Leadership Academy Skills

- **ASK**
 - What do I want?
- **TRUSTWORTHINESS (Ethos)**
 - People listen to us when they get to know us.
 - Skill: Introductions
- **EMOTION (Pathos)**
 - People listen to us when care about what we are saying.
 - Skill: Personal story telling workshop.
- **LOGIC (Logos)**
 - People listen to us when we have facts to support our thoughts.
 - Skill: Research on topics.



Leadership Academy Showcase

- Fellows presented on their advocacy topic using the TEL model
- State and federal partners attended



What is the UCLA Leadership Academy for Emerging Disability Rights Leaders?

A program to teach individuals with lived experience knowledge and skills related to disability policy and advocacy.

**What are the results of the UCLA
Leadership Academy for Emerging
Disability Rights Leaders?**

Pilot Study: Methods

- Fellows were recruited from Tarjan Center, USC/CHLA UCEDD, UC Davis MIND CEDD, DDS, and UCLA Pathway
- 10 fellows enrolled (Range: 20-45 years)
- Range of disabilities
 - Autism
 - Intellectual disability
 - Down syndrome
 - Cerebral palsy



Pilot Study: Methods

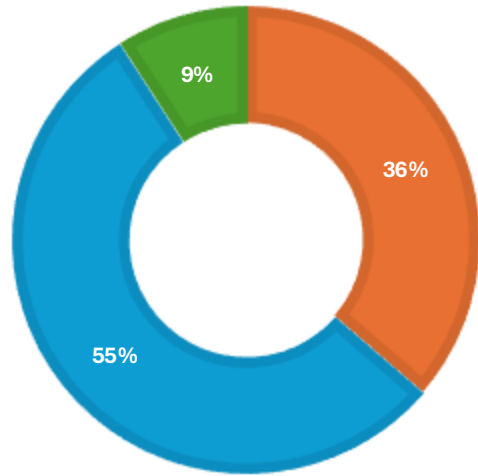
- Program evaluation (feasibility and acceptability) surveys were completed by the fellows
- Questions on Leadership Academy content
 - Knowledge
 - Skills
 - Structure and curriculum



Pilot Study: Demographics

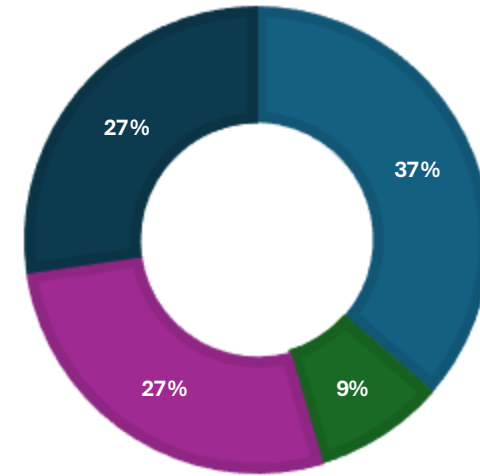
GENDER

Male Female Non-binary



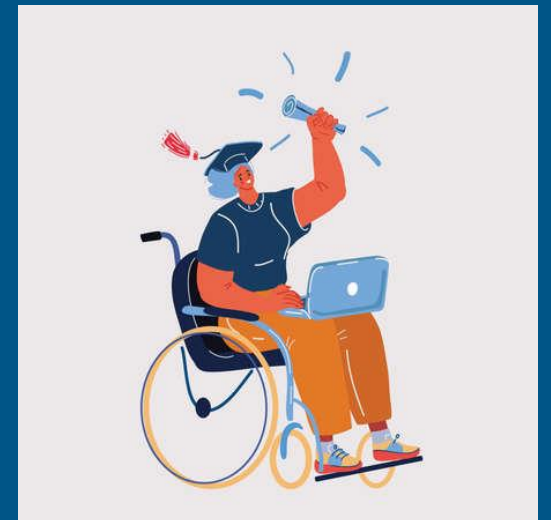
RACE

Asian Black or African American White Preferred not to answer



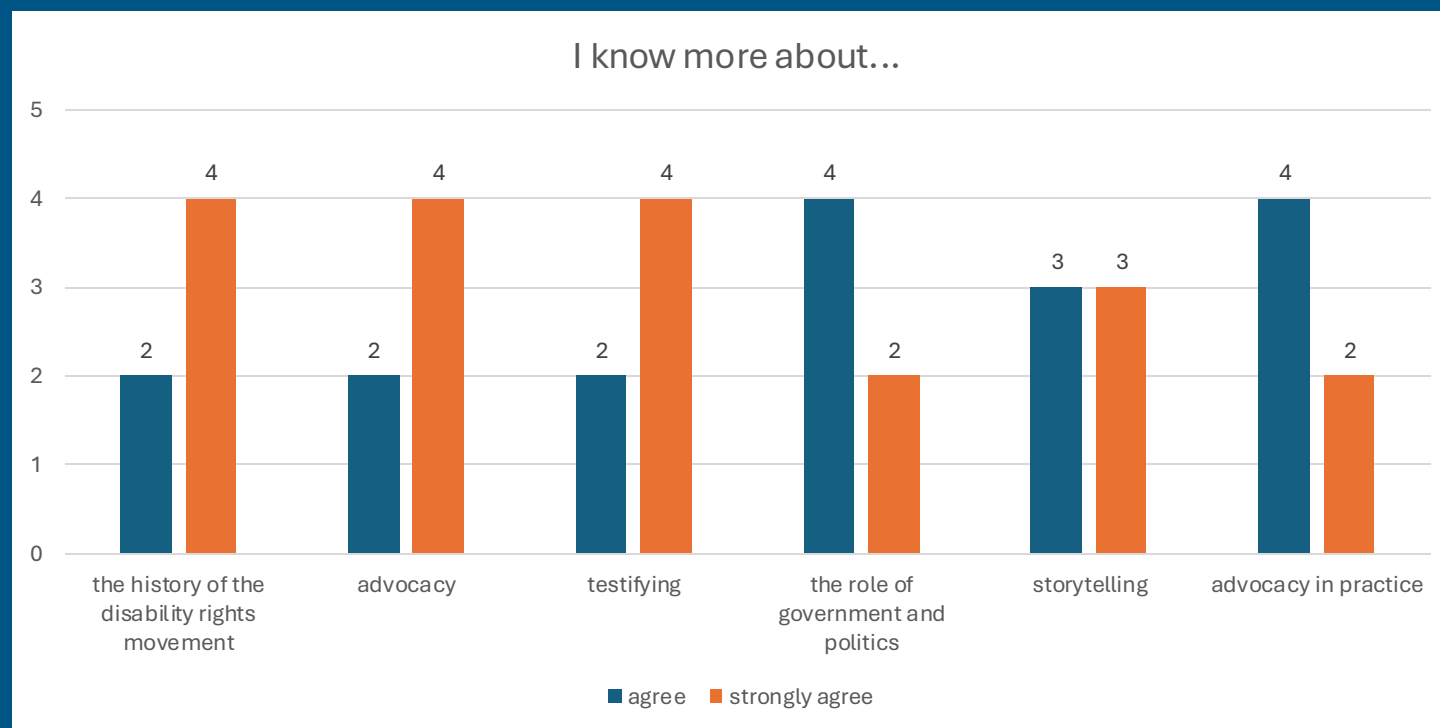
Pilot Study: Results

- 9 fellows graduated ($M_{age} = 26$, $SD = 7.4$)
 - 7 fellows attended $\geq 80\%$ of sessions
- 6 completed the program evaluation survey



Pilot Study: Results

- 100% of respondents *agreed* or *strongly agreed* that their **disability policy and advocacy knowledge** increased



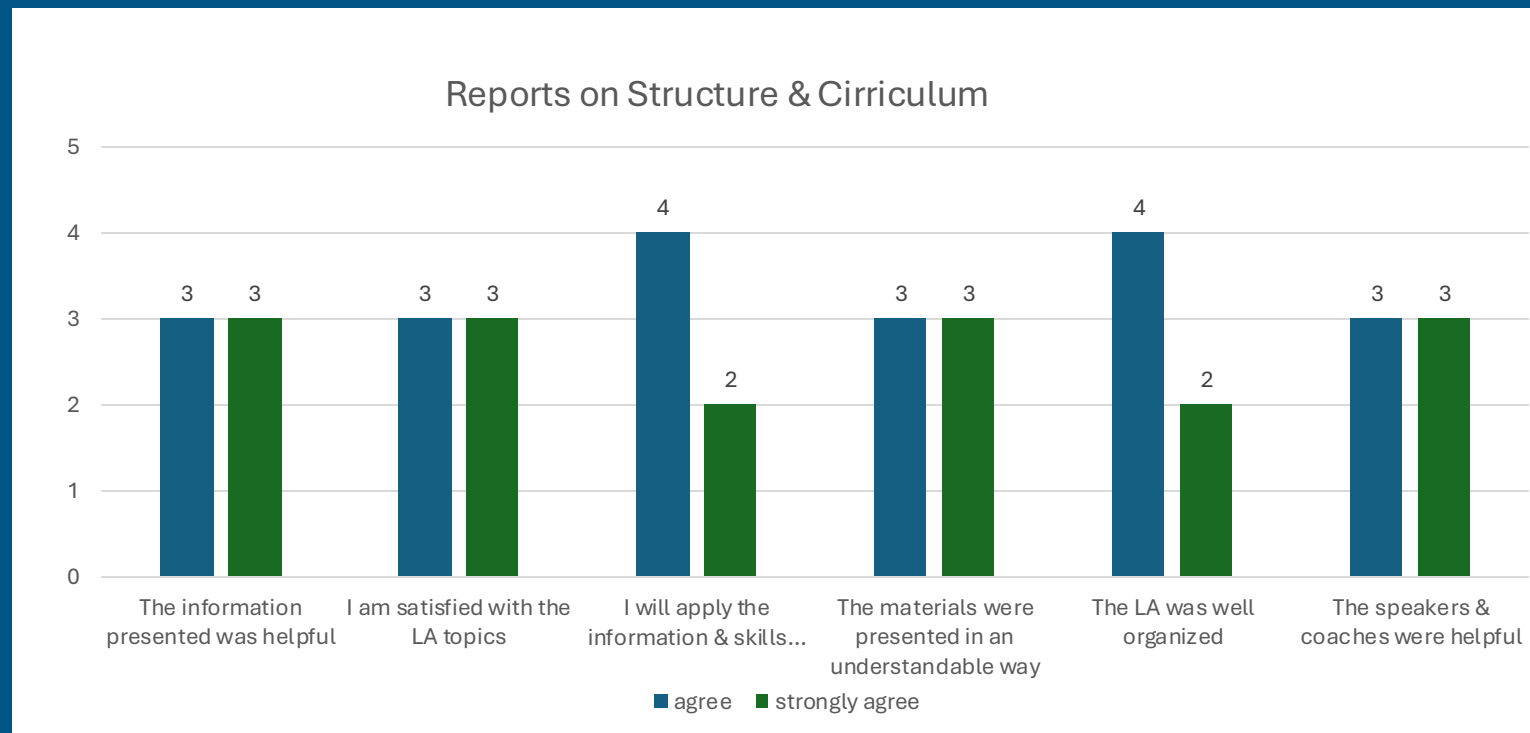
Pilot Study: Results

- 100% of respondents *agreed* or *strongly agreed* that their **disability policy and advocacy skills** improved



Pilot Study: Results

- 100% of respondents *agreed* or *strongly agreed* that the **Leadership Academy structure and curriculum** was helpful



Pilot Study: Results

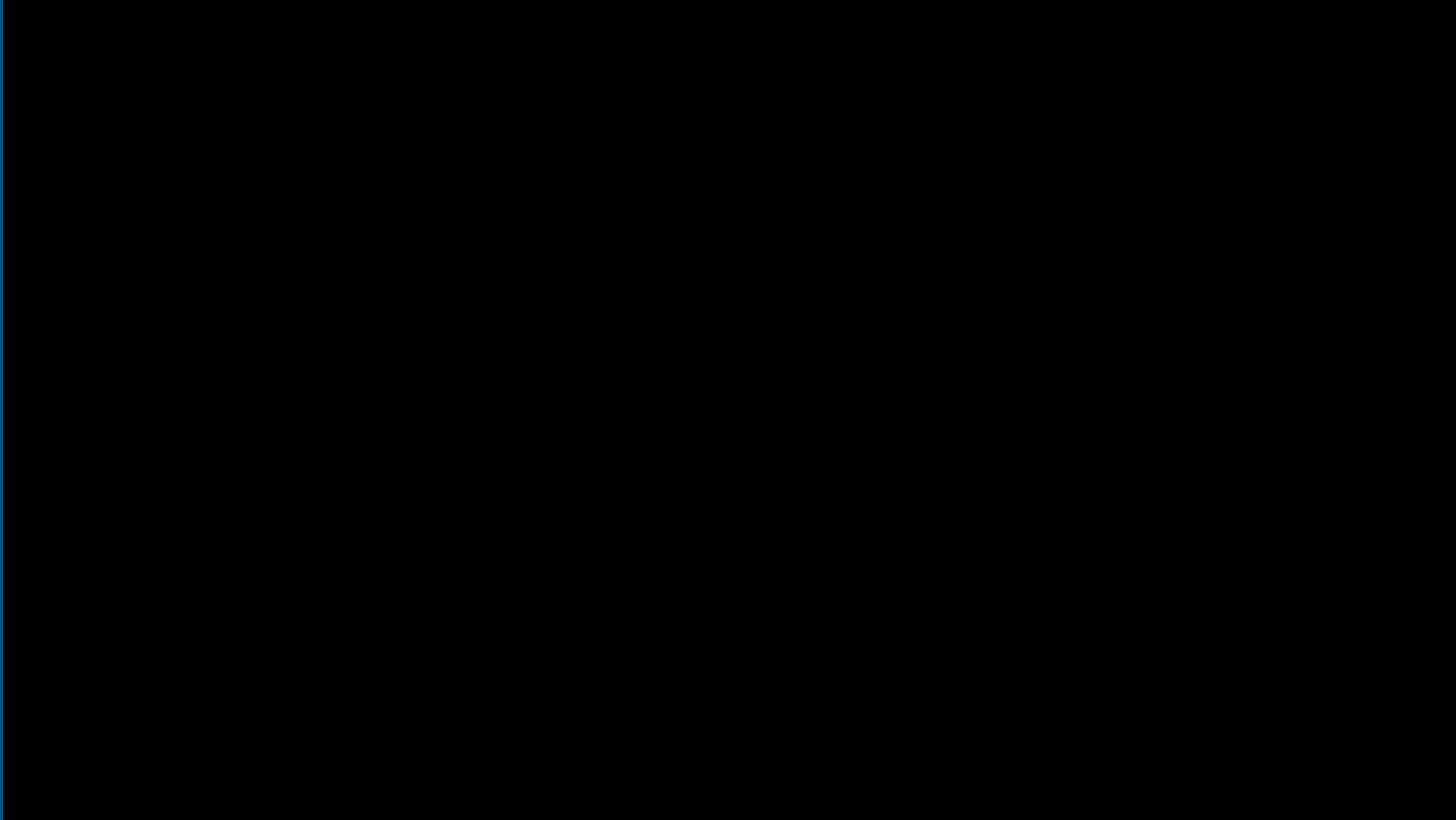
- 33% were interested in learning more about current disability rights topics
- 33% were interested in self-advocacy in the workplace or classroom
- 83% ranked the session Advocacy in Practice as one of the most helpful

Pilot Study: Results

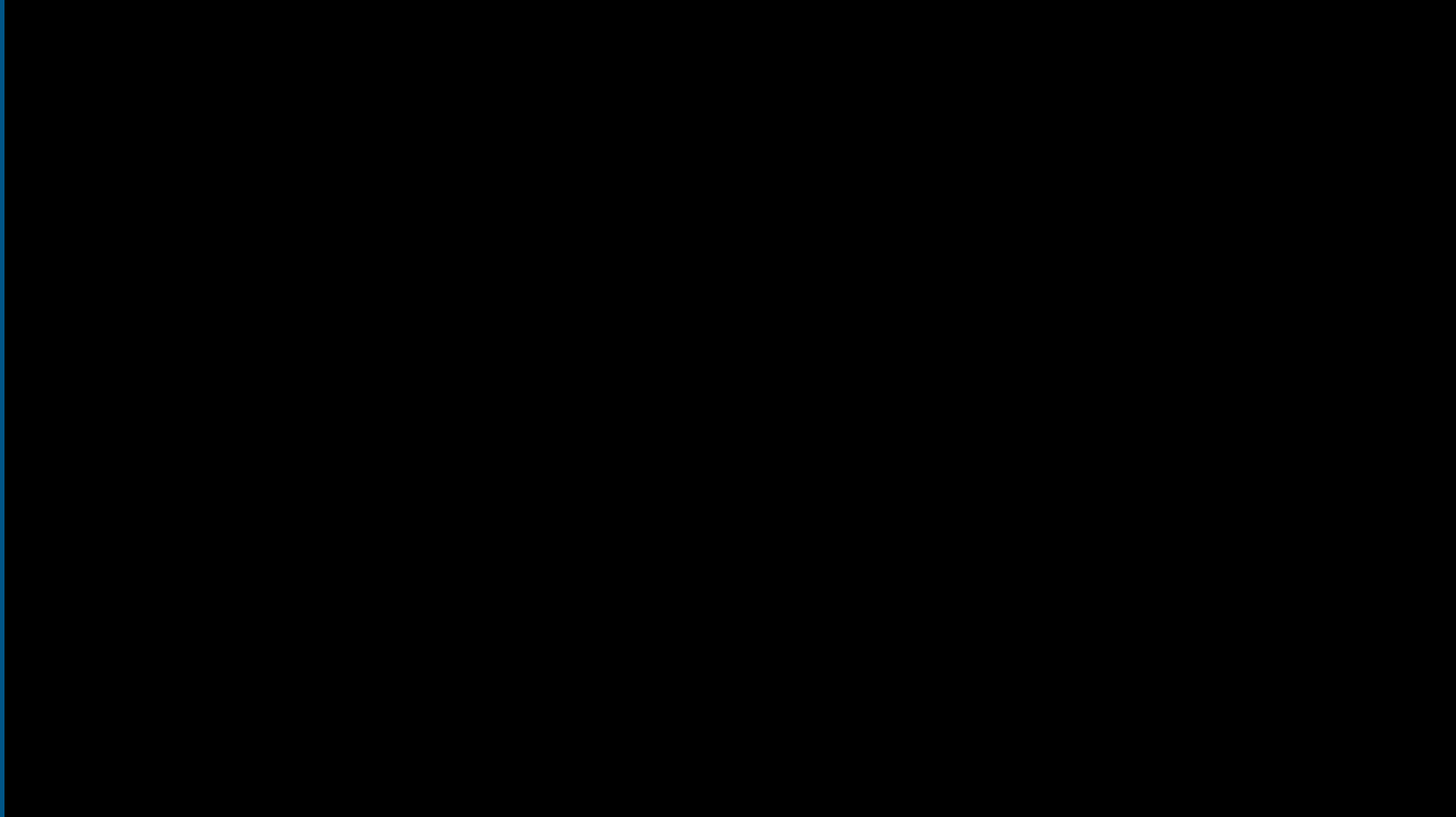
**“My main goal
is to become a
disability advocacy
leader in my
workplace”**

**“I WOULD LIKE TO
LEARN WHAT
LEADERSHIP
MEANS”**

Fellow Experience: Holly



Coach & Instructor Experience: Kecia



What are the results of the UCLA Leadership Academy for Emerging Disability Rights Leaders?

It is helpful for teaching knowledge and skills related to disability policy and advocacy.

**What is next for the UCLA Leadership
Academy for Emerging Disability Rights
Leaders?**

Future Directions

- Introduce skills earlier and give more structured support
 - Assign Leadership Coach and Senior Fellow for each fellow
- Coaching Academy
- Include content on current disability policy topics

What is next for the UCLA Leadership Academy for Emerging Disability Rights Leaders?

We have a lot planned! 😊

Conclusions

- Leadership Academy is both feasible and acceptable for individuals with lived experience
- Highlights importance of teaching skills related to disability policy and advocacy



THANK YOU!

- Our wonderful fellows, speakers, and leadership coaches
- Kecia Weller, Wesley Witherspoon, and Holly Oliver
- Our collaborators: Drs. Kashia Rosenau and Alice Kuo (UC-LEND)
- Our state and federal partners: SCDD, DRC, UC Davis MIND, USC/CHLA
- Elsa Cincione, MA

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