The LEND Outcomes Follow-Up Survey: Development and Preliminary Findings

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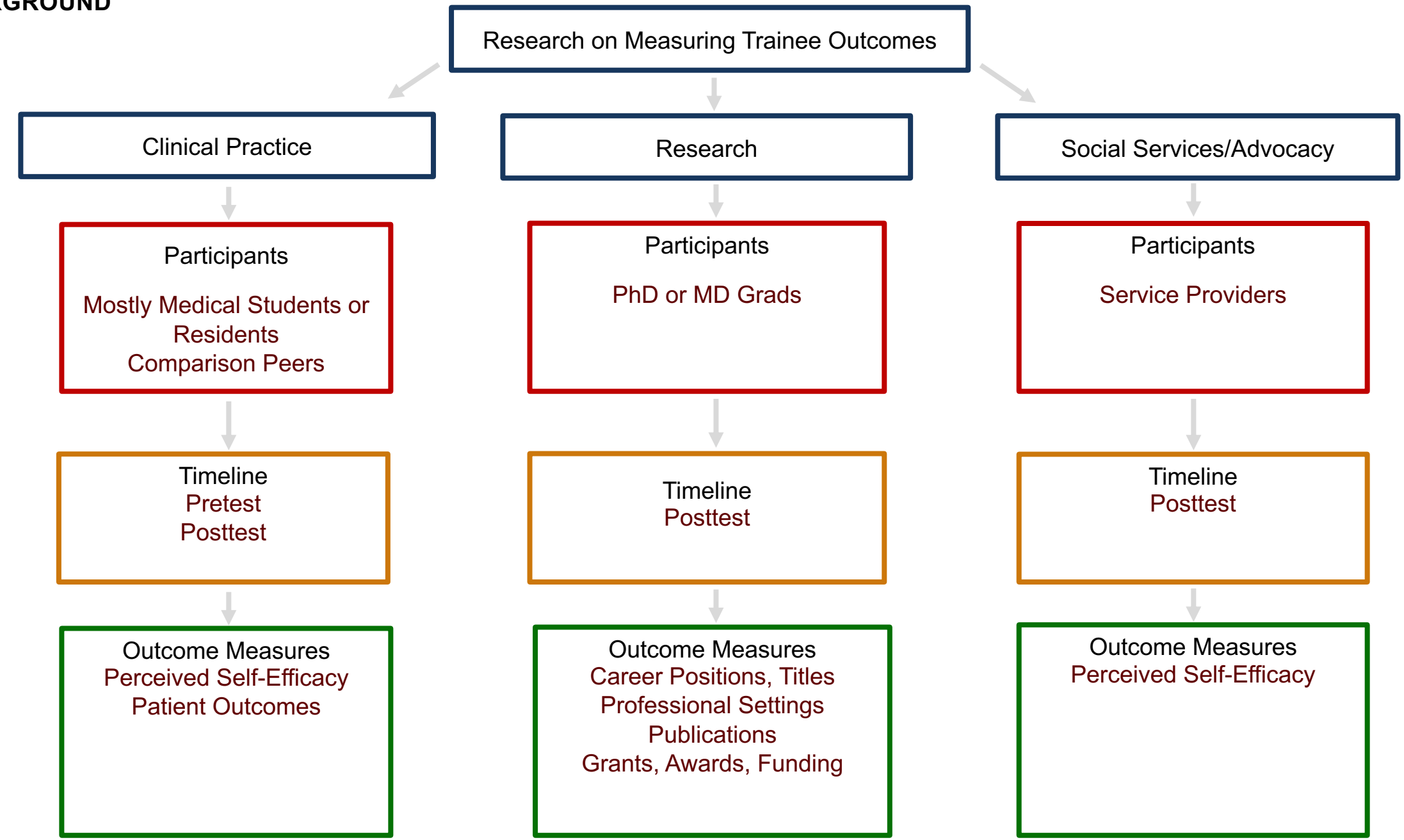
UNDERSTANDING LEND'S EFFECTIVENESS

- Does LEND training deliver?
- Current funding climate for programs, services, and research
- Your tax dollars at work

Background


Research on Measuring Trainee Outcomes
Clinical Practice
Research
Social Services/Advocacy
Participants
Mostly Medical Students or Residents
Comparison Peers
Participants
PhD or MD Grads
Participants
Service Providers
Timeline
Pretest
Posttest
Timeline
Posttest
Timeline
Posttest
Outcome Measures
Perceived Self-Efficacy
Patient Outcomes
Outcome Measures
Career Positions, Titles
Professional Settings
Publications
Grants, Awards, Funding
Outcome Measures
Perceived Self-Efficacy

HOW ARE LEND TRAINEE OUTCOMES TYPICALLY MEASURED?

- NIRS Survey (*the survey LEND Directors love to hate*)
  - Common program evaluation technique
  - Comparison of long-term to short-term trainees (Kavanagh et al., 2015)
- New Techniques
  - Faculty observation of family centered and interprofessional care using the I-FOR (Brosco et al. 2018)
- Studies generally find that:
  - Trainee skills improve during LEND training (Brosco et al. 2018)
  - Long-term trainees are more likely to work on interdisciplinary teams and with MCH and vulnerable populations (Kavanagh et al., 2015)

ALL THAT GLITTERS IS NOT GOLD:

Could previous positive effects of LEND be caused by something other than LEND training?

THE LEND OUTCOMES STUDY

- Multi-site (Pittsburgh, Nisonger, Waisman)
- Matched case control study
  - Closest ethically and programmatically feasible methodology to randomized controlled trial
- Prospective
- Longitudinal (at least 10 years; currently in year 4)

THE OHIO STATE UNIVERSITY
NISONGER CENTER

WAISMAN CENTER
UNIVERSITY OF WISCONSIN-MADISON

PG LEND

LEND Outcomes Study Timeline

2015 Cohort Timeline

2014-2015

LEND Outcomes Study Initiated

81 Participants

81 Participants

Withdrawals: 0
NIRS Completion Rate: 100%

Developed Manual
Pitt Partnered with
Nisonger and Waisman

2015-2016

79 Participants

Withdrawals: 2
NIRS Completion Rate: 100%

Revised Manual Based on Feedback from Other Sites

2016-2017

LEND Outcomes Follow-Up Survey Study Initiated

Withdrawals: 0
NIRS Completion Rate: 88.6%

AUCD Feasibility Presentation

ITAC Grant Received
Initial LEND Outcomes Follow-Up Survey Development

2017-2018

LEND Outcomes Follow-Up Survey Pilot

74 Participants

Withdrawals: 0
NIRS Completion Rate: 91.1%

Analysis of Data from 3rd Year NIRS Survey

AUCD Focus Groups
Survey Pilots
Data Analysis
AUCD Outcomes Presentation

Key:
- LEND Outcomes Study
- LEND Outcomes Follow-Up Survey Study

LEND Outcomes Follow-Up Survey

- Initial core competency survey developed based on “expert” opinion of trainee skills and competencies
- Surveyed non-trainees in research labs

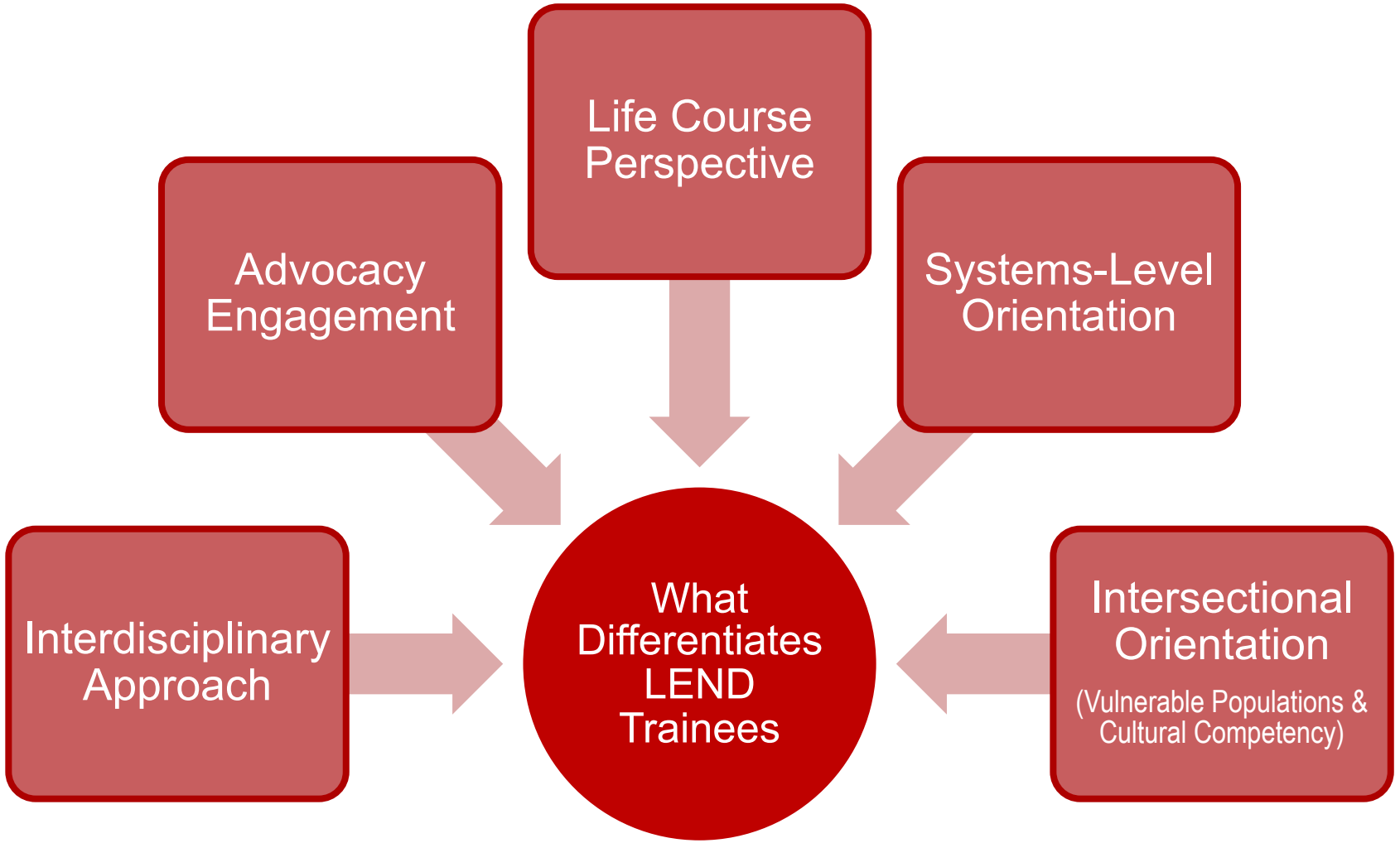
Non-trainees thought that their skills in LEND Core Competencies were excellent

Focus Groups

- 2017 AUCD Annual Meeting
- Questions:
  - What types of leadership roles are you training your trainees to take on?
  - What makes LEND graduates different from their peers who did not receive LEND training?
  - How are you defining MCH populations with your trainees?
- Transcribed and analyzed using content analysis

Focus Groups: Five Themes

The "Active Ingredients" of LEND Training



In clinical trials, the "active ingredients" should align with how treatment effects are measured…

Other Possible "Active Ingredients":

- Leadership
- Engagement with disabilities/SHCN
- Research experience

Back to the Drawing Board

Faculty Pilot Process and Results

- Piloted with 14 LEND and non-LEND faculty members and family stakeholders
- Feedback obtained from AUCD staff
- Took, on average, 25.29 minutes to complete
- Suggestions to:
  - Remove redundancy
  - Reduce focus on academic positions and academic leadership
  - Add questions: MCH competencies, core LEND leadership skills, job satisfaction and reason for taking current position

Revisions Based on Faculty Pilot

- Reduced long and burdensome questions
- Removed redundancy
- Reduced focus on academia and academic leadership
- Added questions about:
  - MCH competencies
  - Core LEND leadership skills
  - Job satisfaction and reason for taking current position

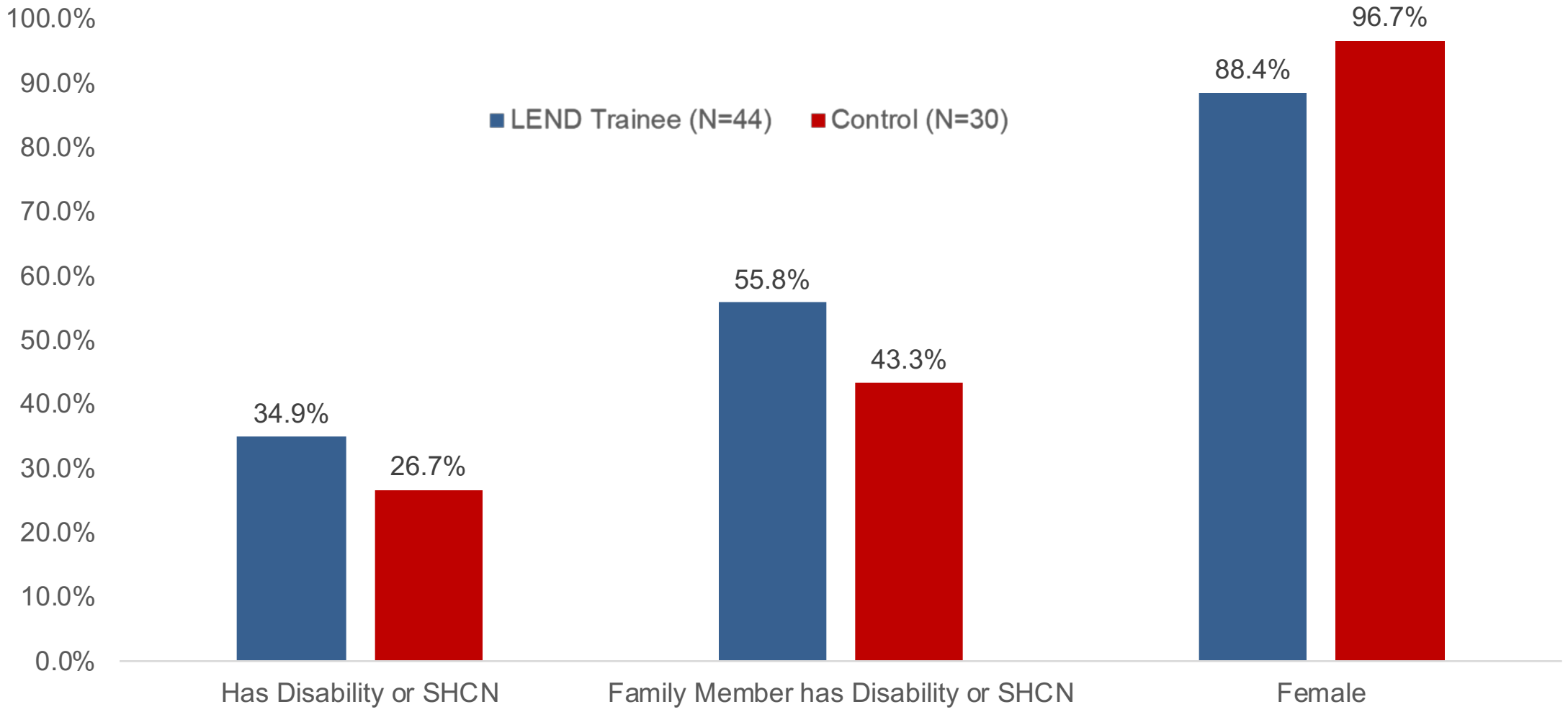
LEND Outcomes Follow-Up Survey

- 31 questions
- Administered via RedCap through UW-Madison
- Informed consent obtained

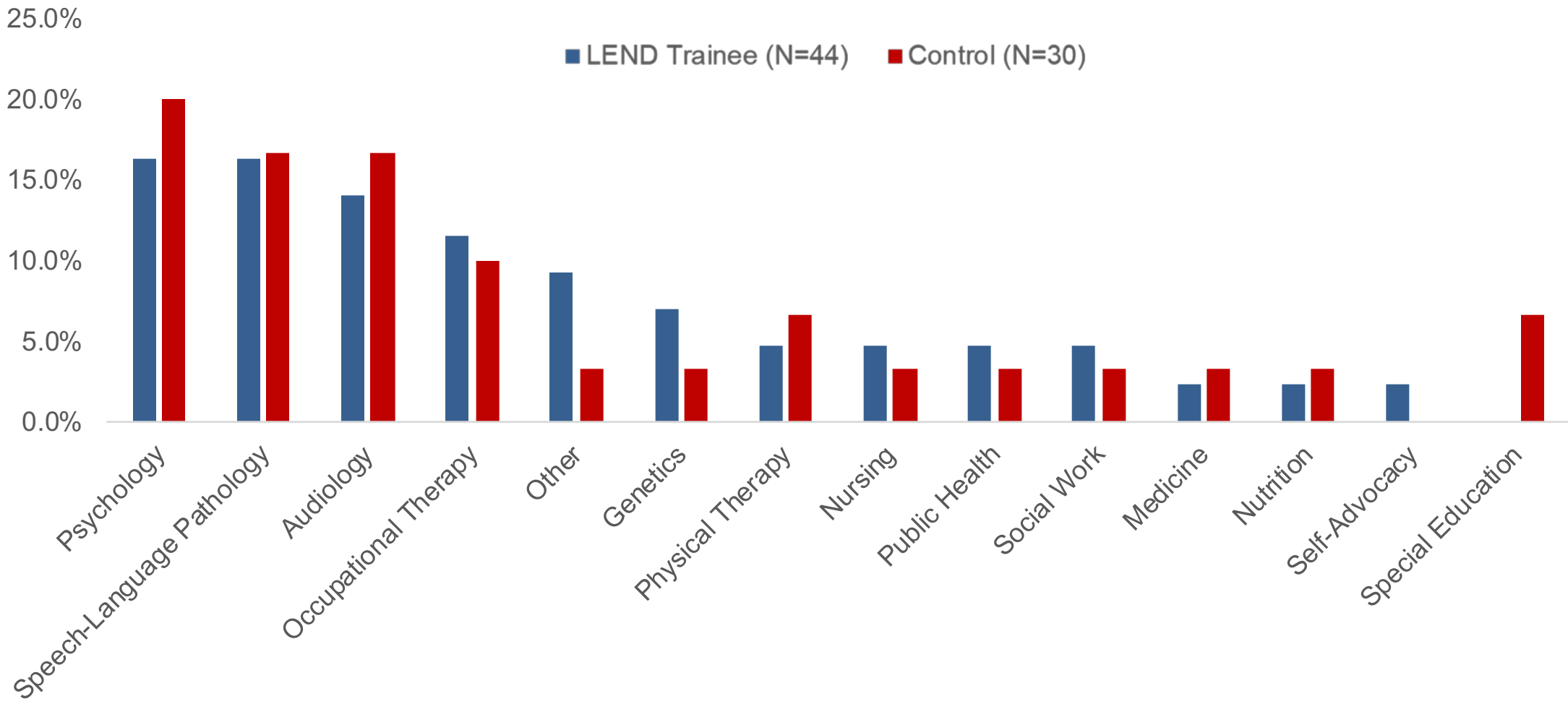
FEASIBILITY

- Recruited 93.7% of eligible participants (74 out of 79)
- Took participants, on average, 24:45 to complete the survey
- No missing data
- Cost: $25 compensation per completed survey

PARTICIPANT BACKGROUND CHARACTERISTICS

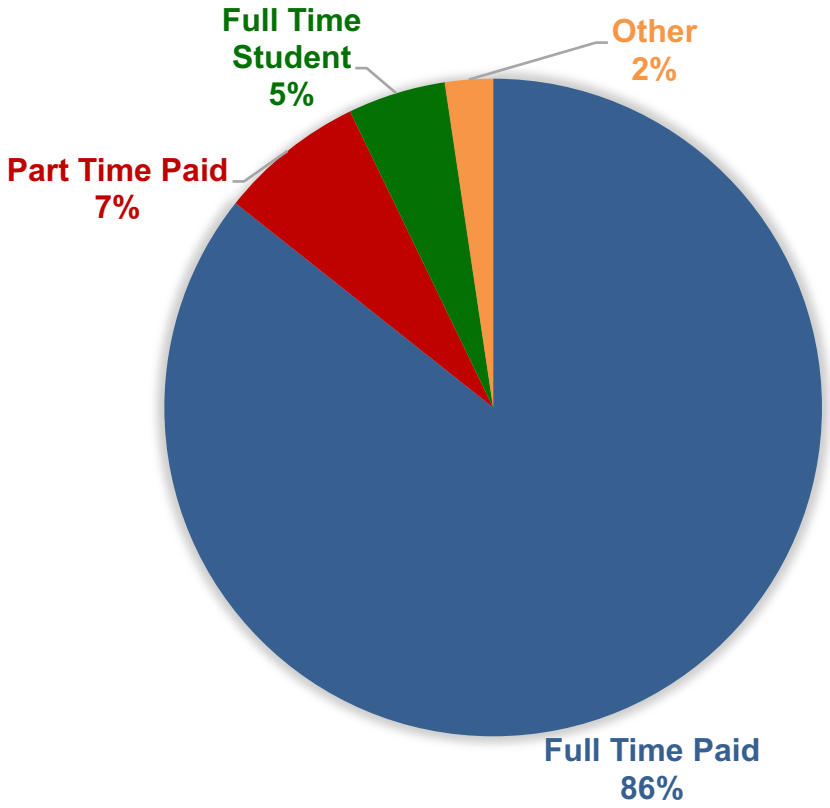


PARTICIPANT DISCIPLINES

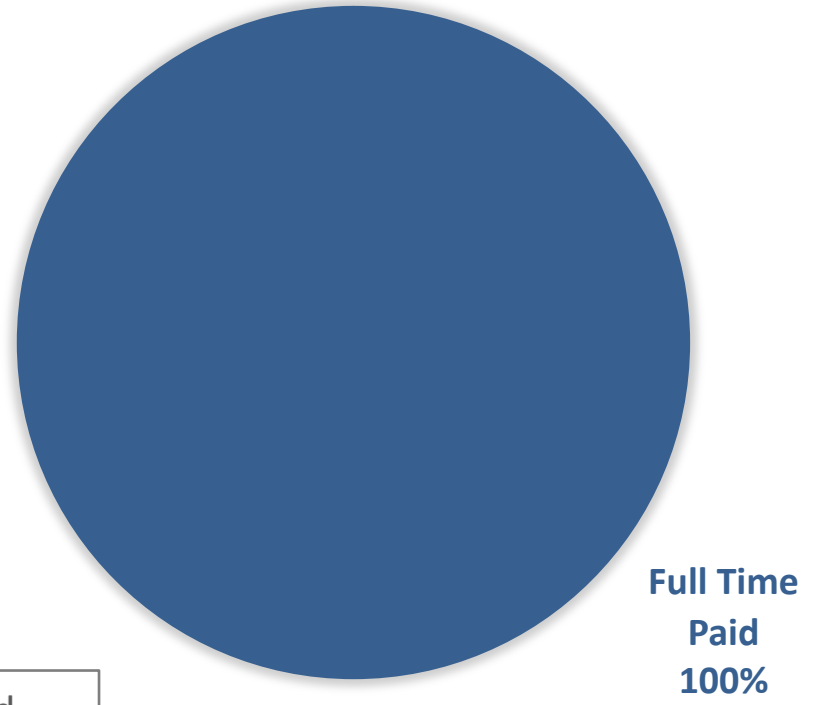


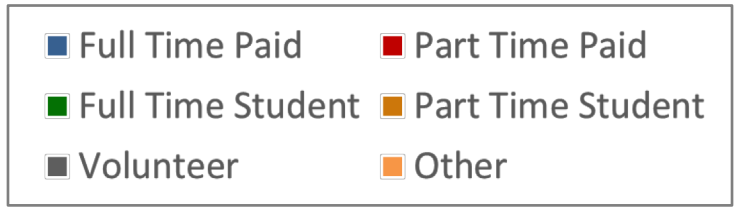
PARTICIPANT WORK TYPE

LEND Trainee (N=44)

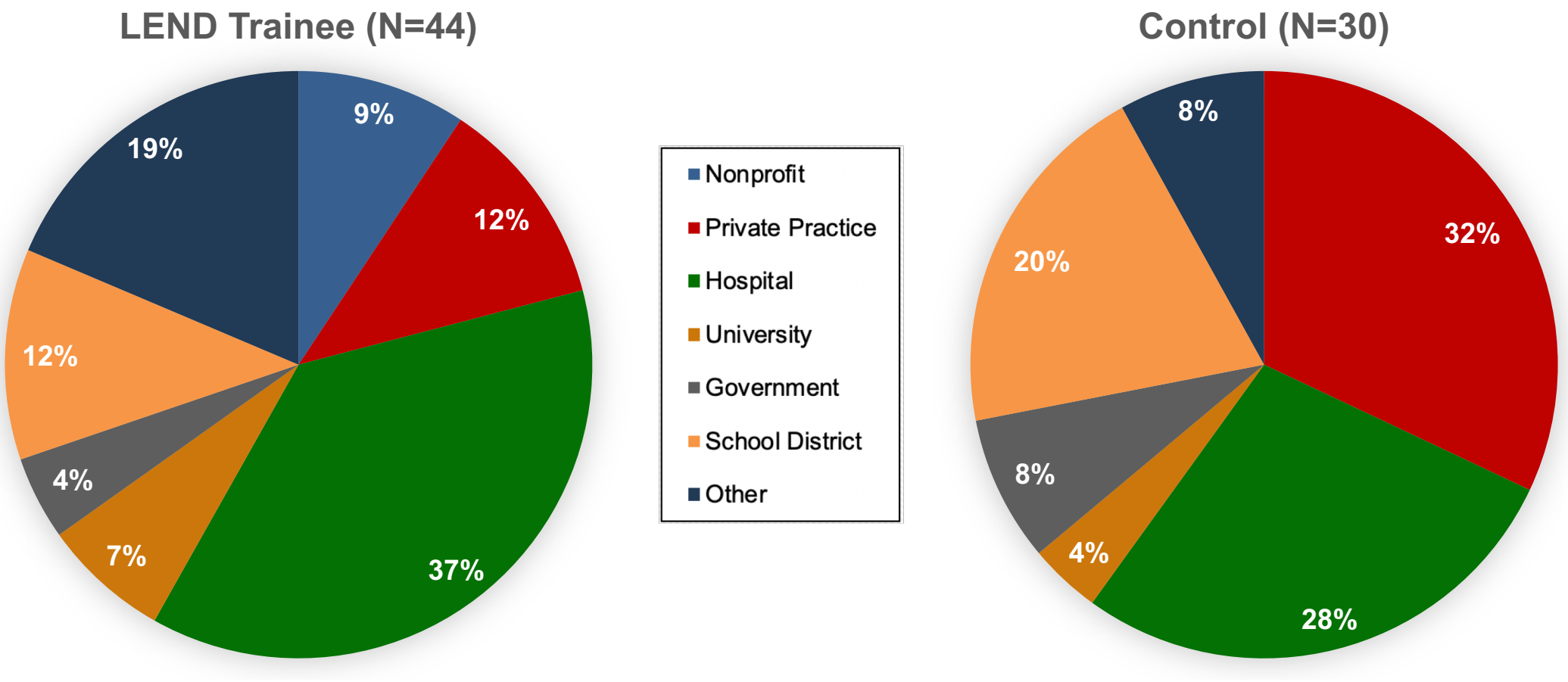


Control (N=30)



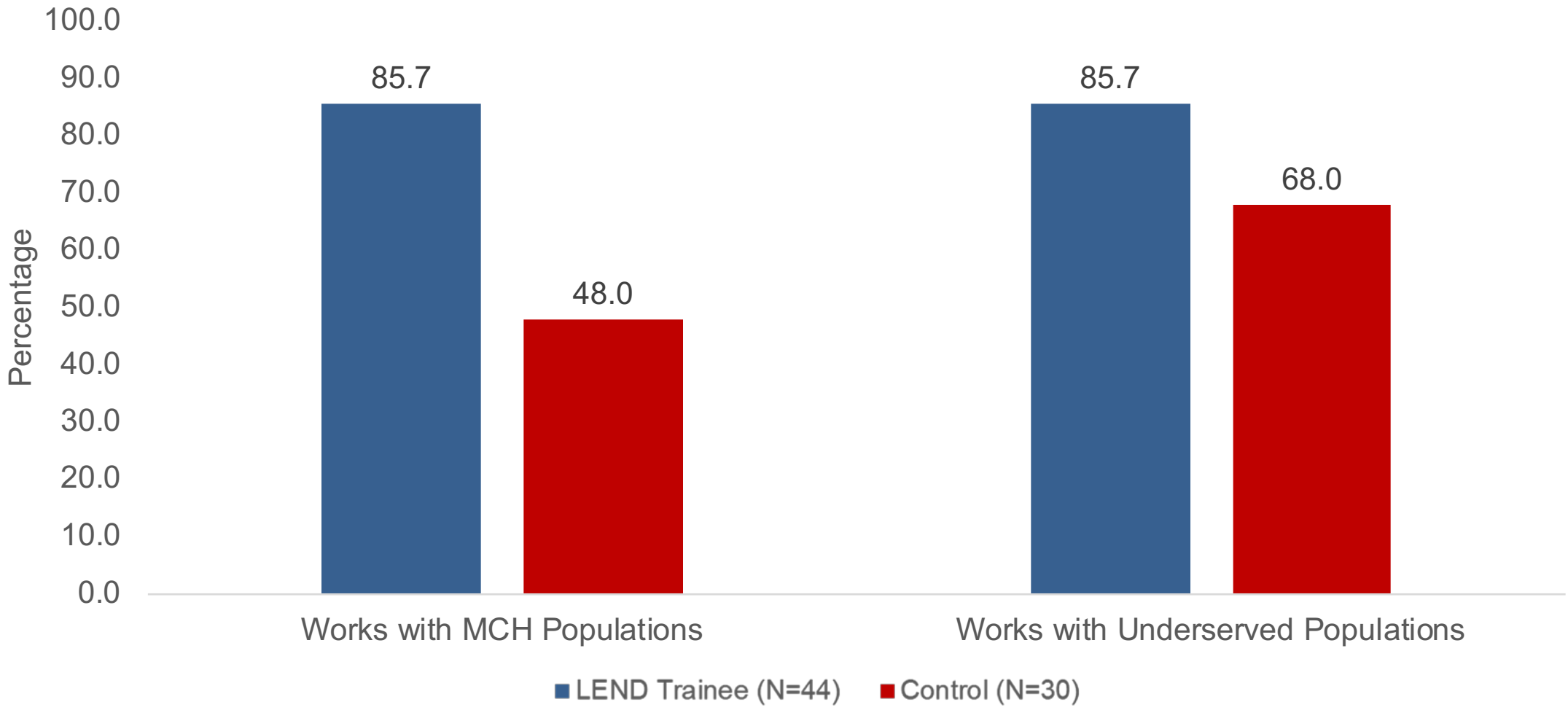


PARTICIPANT WORK SETTINGS



NIRS

(SIGNIFICANT DIFFERENCES)



NIRS

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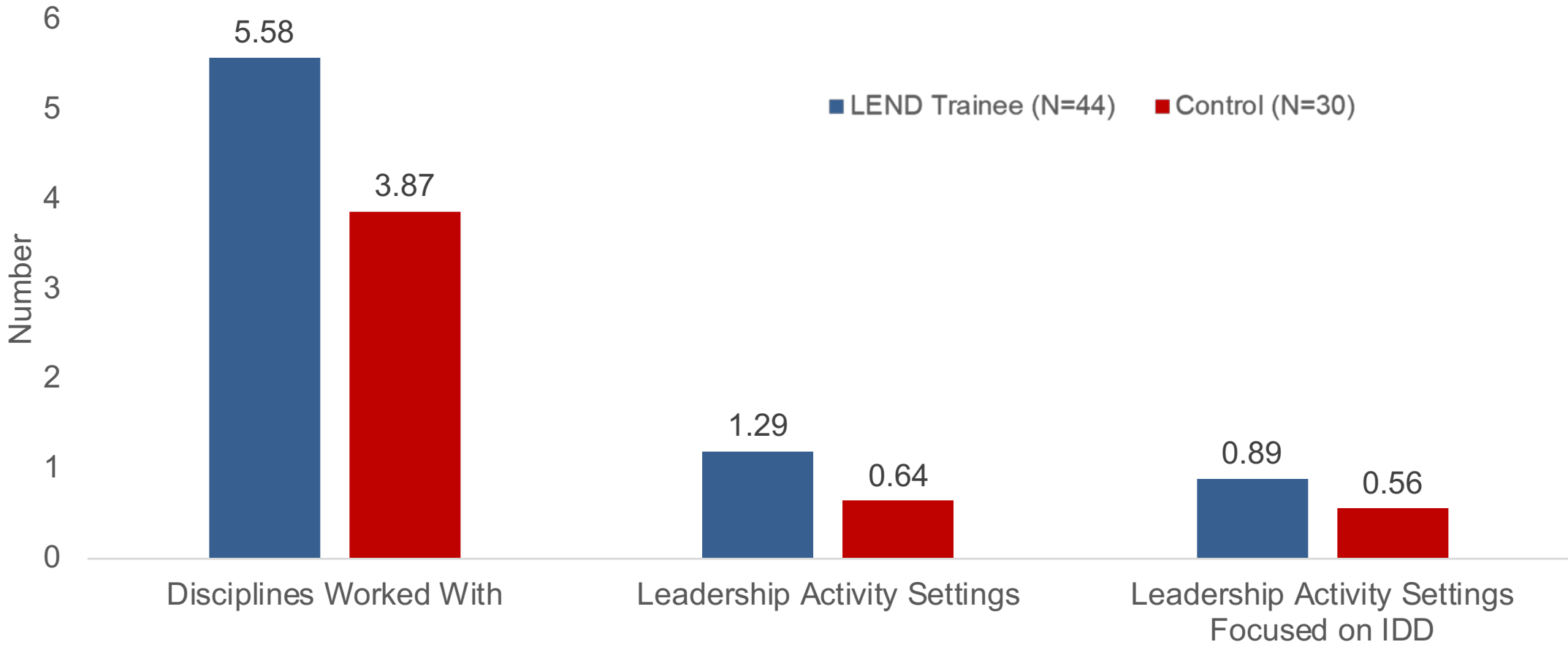


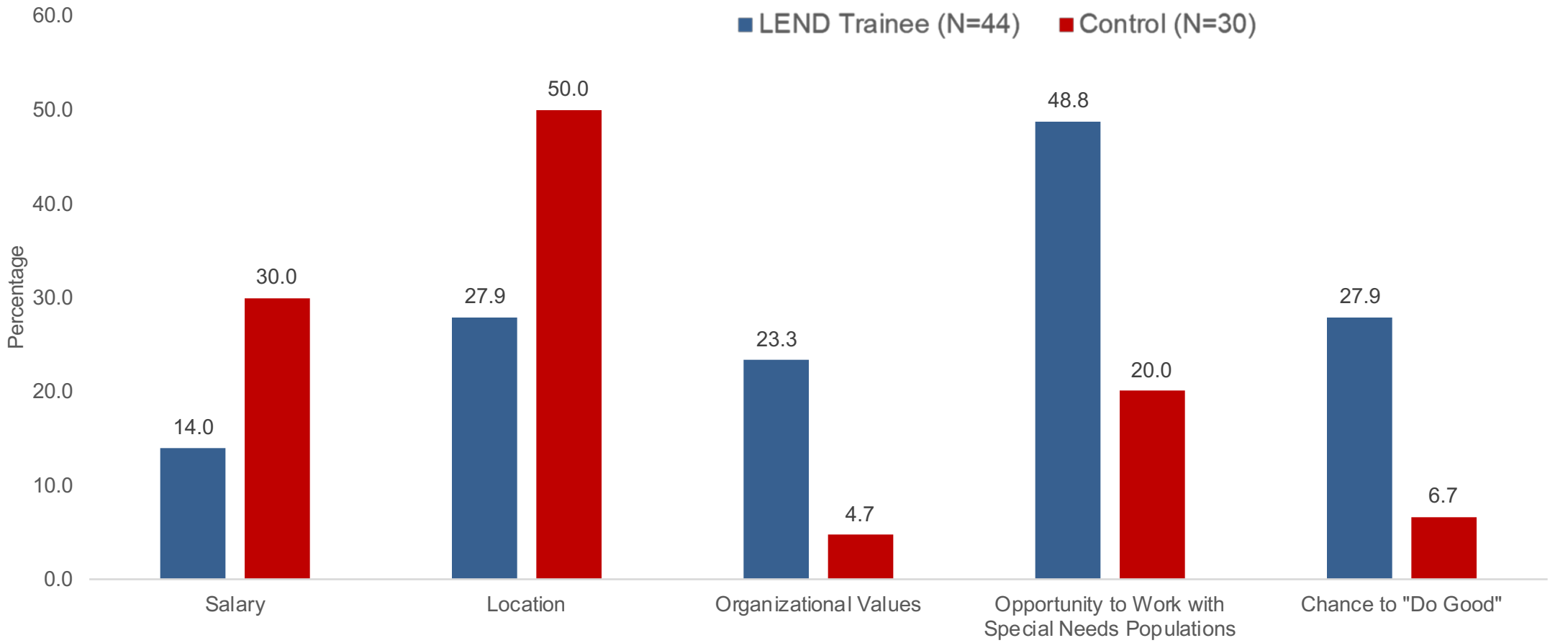
NIRS

(DIFFERENCES THAT ARE NOT SIGNIFICANT)

- Proportion who work with individuals with disabilities
- Type of employment setting
- Number of people served via direct services

LEND OUTCOMES FOLLOW-UP SURVEY

(SIGNIFICANT DIFFERENCES)



ITEMS LISTED AS TOP 3 REASONS FOR ACCEPTING CURRENT POSITION

LEND OUTCOMES FOLLOW-UP SURVEY

(SIGNIFICANT DIFFERENCES)

23. In the past year, have you:

Advocacy

a. supported a family or individual by advocating for their legal or medical rights?
☐ Yes ☐ Not this year ☐ Never

b. participated in a family or self-advocacy group or organization for individuals with special needs?
☐ Yes ☐ Not this year ☐ Never

c. helped a family or individual with their own self-advocacy efforts?
☐ Yes ☐ Not this year ☐ Never

Resource Brokering

d. assisted a family or group of families in finding an appropriate advocacy and/or support group?
☐ Yes ☐ Not this year ☐ Never

e. identified and shared community resources to address a family's or group of families' needs?
☐ Yes ☐ Not this year ☐ Never

f. identified and/or accessed financial resources to assist a family in meeting their needs?
☐ Yes ☐ Not this year ☐ Never

Research

g. communicated research findings to colleagues or a professional group?
☐ Yes ☐ Not this year ☐ Never

h. participated in program evaluation on the effectiveness of a service delivery system?
☐ Yes ☐ Not this year ☐ Never

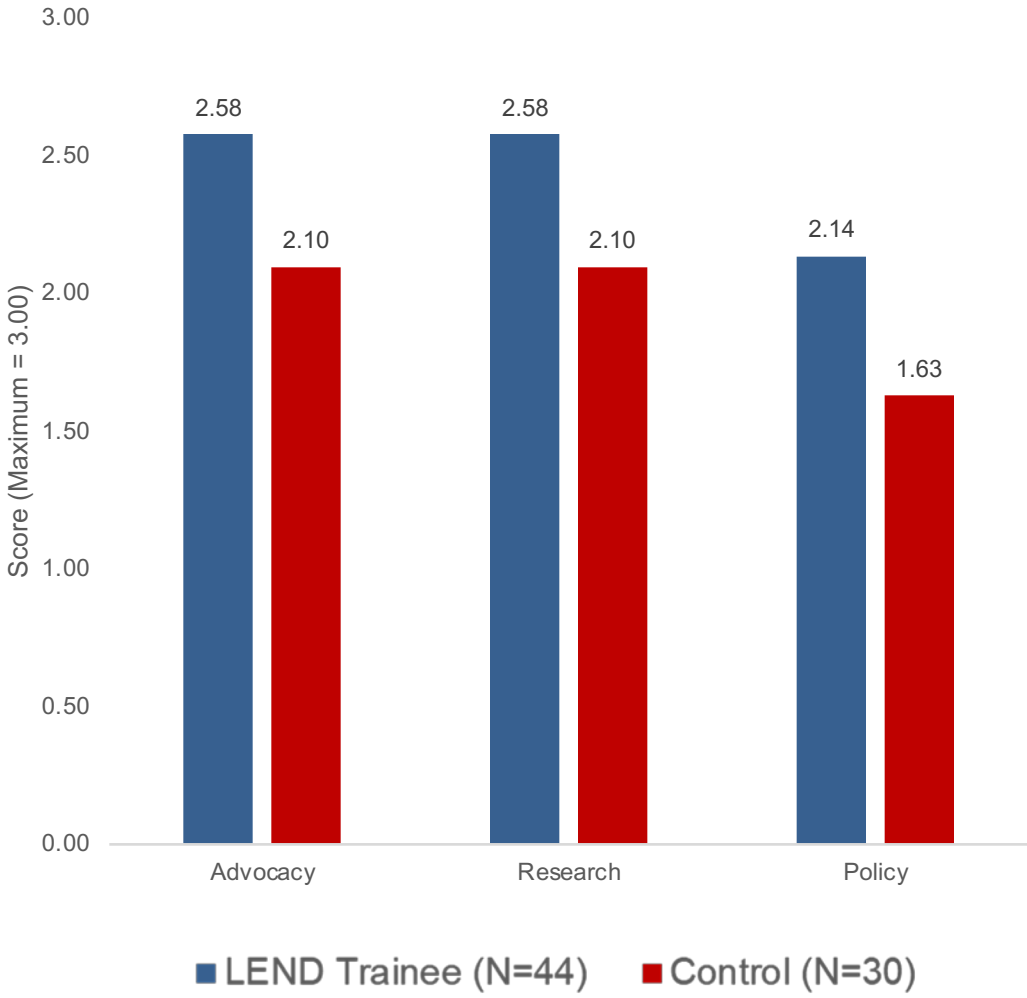
i. participated in research related to vulnerable populations?
☐ Yes ☐ Not this year ☐ Never

Policy

j. evaluated a health care policy for your own or another organization?
☐ Yes ☐ Not this year ☐ Never

k. called, emailed or met with your federal or state legislators or member of their staff on an issue related to individuals with special needs?
☐ Yes ☐ Not this year ☐ Never

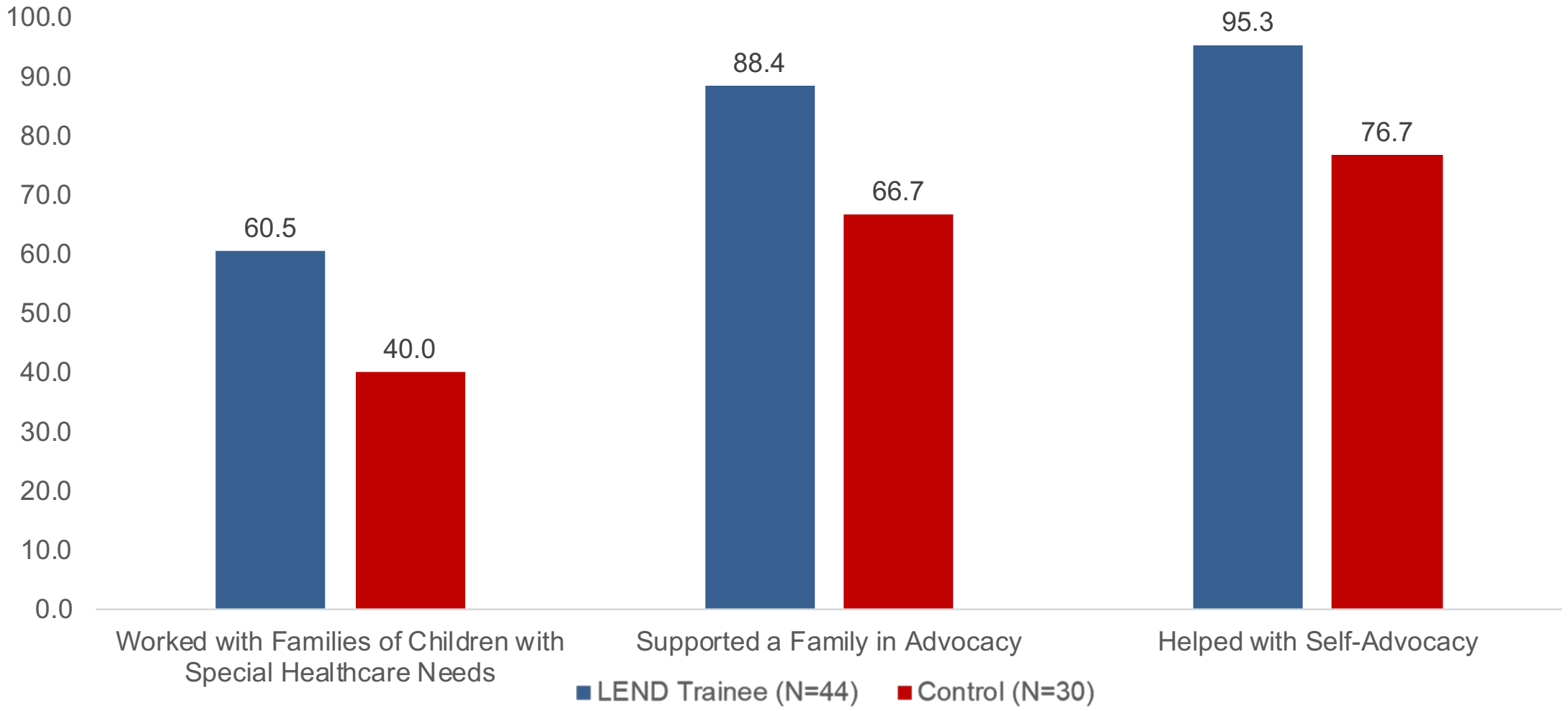
l. participated in an effort related to systems change (e.g., clinical or public health quality improvement, writing policy or clinical guidelines, translating evidence-based research to practice)?
☐ Yes ☐ Not this year ☐ Never



Resource Brokering was NOT Significant

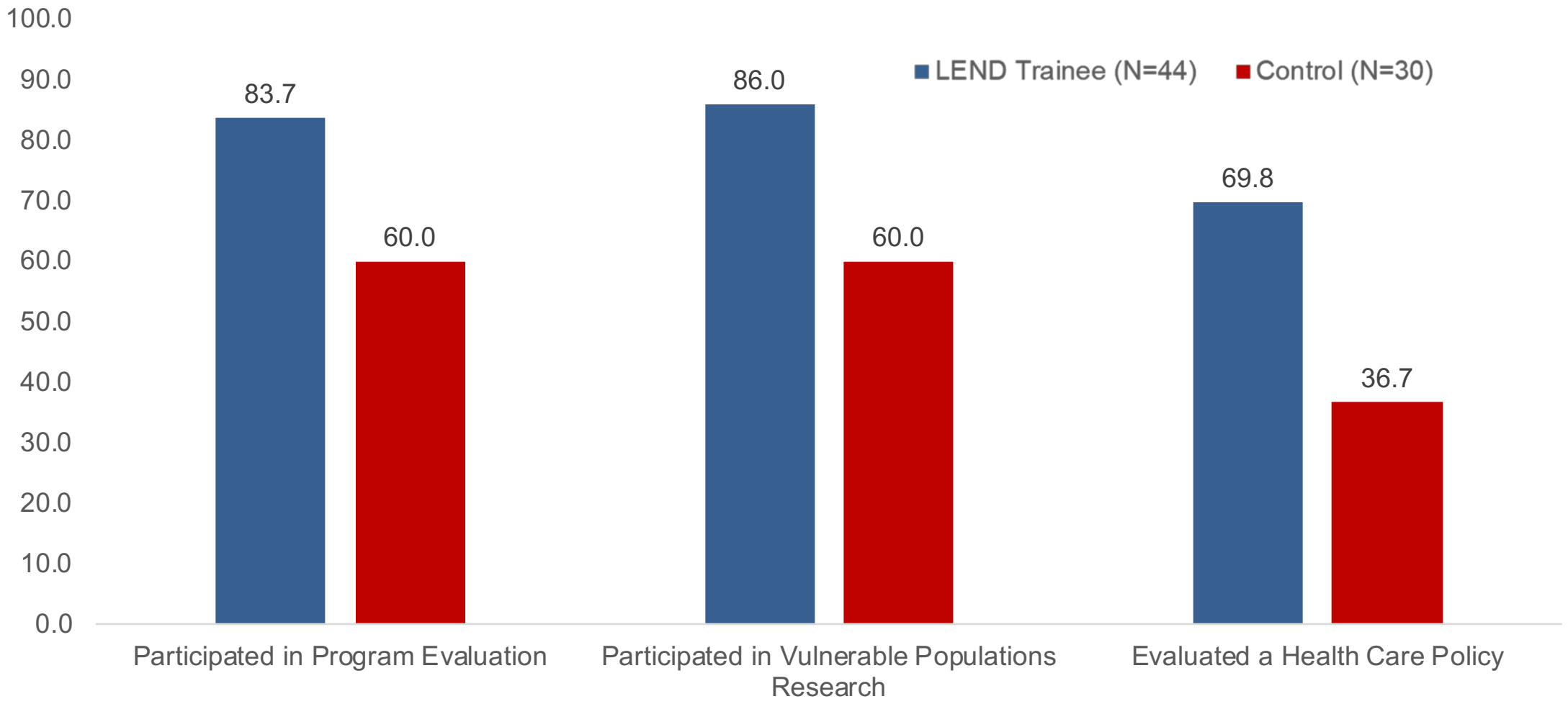
LEND OUTCOMES FOLLOW-UP SURVEY

(SIGNIFICANT DIFFERENCES)



LEND OUTCOMES FOLLOW-UP SURVEY

(SIGNIFICANT DIFFERENCES)



LEND OUTCOMES FOLLOW-UP SURVEY

(DIFFERENCES THAT ARE NOT SIGNIFICANT)

- Workplace characteristics
- Distribution of work time across activities
- Perception of leadership in workplace
- Comfort with **MCH and LEND skills and competencies**
- Agreement with **intersectional orientation** and **life course perspective** concepts
- **Interdisciplinary** teaming
- Job satisfaction

BENEFITS OF LEND

- LEND trainees are more likely to:
  - Work with MCH populations
  - Work with vulnerable populations
  - Endorse high-level leadership skills
  - Work on interdisciplinary teams
  - Participate in research
  - Participate in advocacy
  - Participate in policy practice

LEND DOES NOT IMPACT

- Type of role or workplace
- Endorsement of agreement with:
  - MCH skills and competencies
  - LEND skills and competencies
  - Intersectional orientation
  - Life course perspective

IMPLICATIONS AND FUTURE DIRECTIONS

- Strong methodology → increased confidence in findings
- Preliminary interpretation: identified significant differences: **perspectives** vs. **actual activities**
  - Both LEND trainees and comparison peers **self-report** that they are leaders and utilize MCH and LEND skills and competencies**, but**
  - LEND trainees **actual work activities** included significantly more leadership activities
- Results are preliminary and analysis is ongoing: need feedback from LEND Network
- Future: publication of results; refinement of survey; more data collection

Acknowledgements

Grant Funding:

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Important People:

- AUCD Staff (Sarah DeMaio, Christine Liao, Ben Kaufmann)
- LEND staff at Pitt, Waisman, and Nisonger
- LEND trainees and comparison peers who participated

The Ohio State University
Nisonger Center

Waisman Center
University of Wisconsin-Madison