

The Role of People with Disabilities in LEND Programs: Results of a National Survey

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Background

- LEND programs train future leaders in the field of neurodevelopmental disability, policy and advocacy
- People with disabilities (PWD) are involved in LEND programs across the network in various roles; however, the type and extent of participation by PWD varies across programs.
- Long-term LEND trainees can be graduate students in professional disciplines, family members of people with disabilities (PWD) or PWD themselves
- Including PWD as long term trainees (LTT) can benefit all trainees
 - PWD gain advanced advocacy and leadership skills, and familiarity with clinical systems.
 - PWD provide expertise of lived experience.
 - Trainees from other disciplines gain a broader perspective about disability, which may shape their future professional practice
- Yet, programs have reported barriers to including PWD as long-term LEND trainees
- LEND PWD Workgroup established 2014.

Objective

- To describe the current participation of PWD in the LEND network
- To identify processes being used to include PWD as long-term trainees
- To assess interest of LEND programs in expanding Self-Advocacy as a separate training discipline

Methods

- Online survey distributed to LEND Directors/Training Directors (n=43) in Jan-Feb 2015
- Response rate 93% (40/43 programs)
- Cross-sectional design
- Ten multiple choice items covering the following topics:
 - Roles of PWD in LEND including as LTT
 - Types of disability
 - Payment
 - Recruitment strategies
 - Training requirements
 - Program interest in developing/growing a category of trainees with disabilities that would be distinct from the family discipline and other disciplines

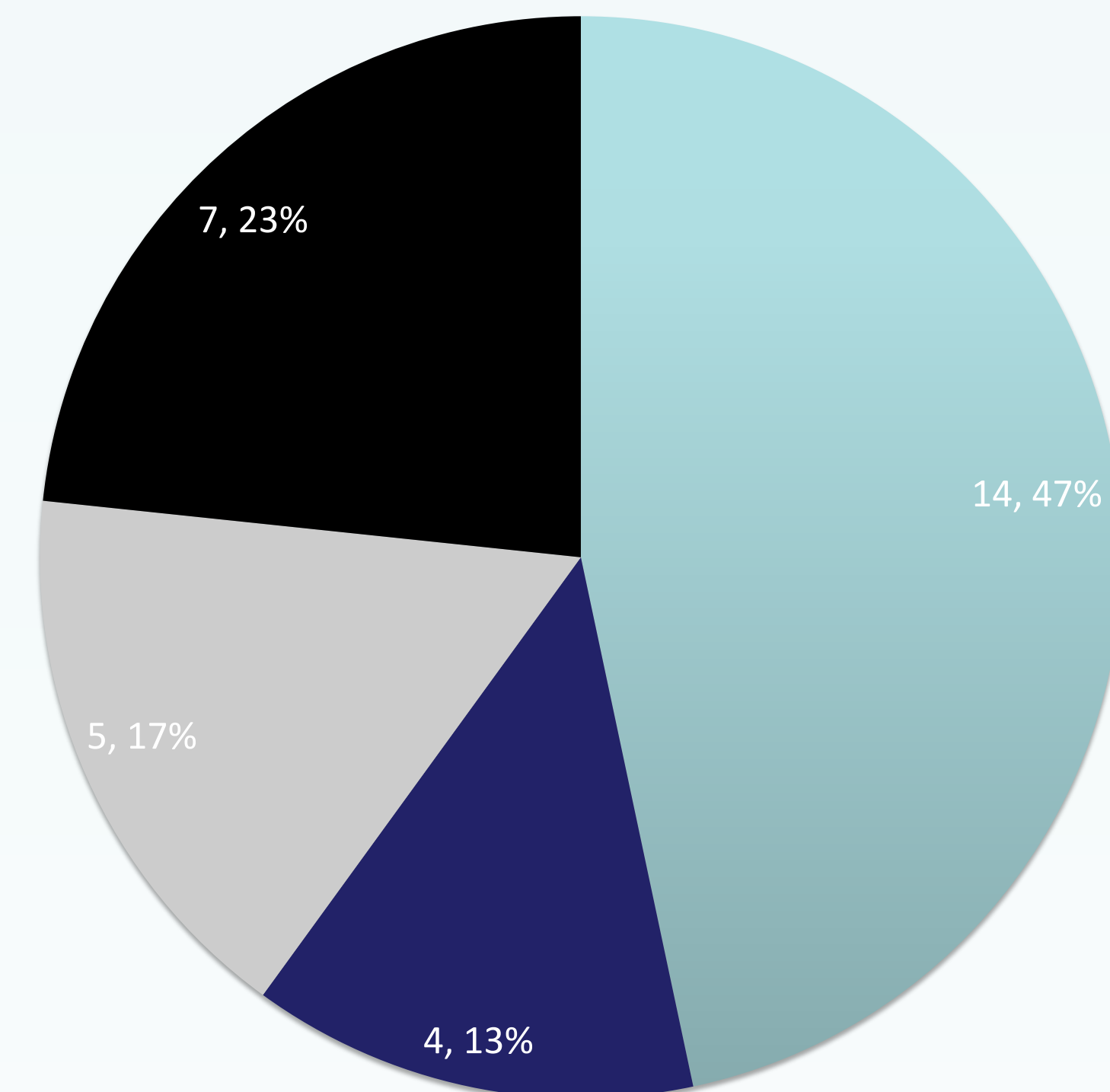
Analysis

Statistical procedures in SPSS were employed to conduct descriptive frequencies

PWD as Long-term Trainees

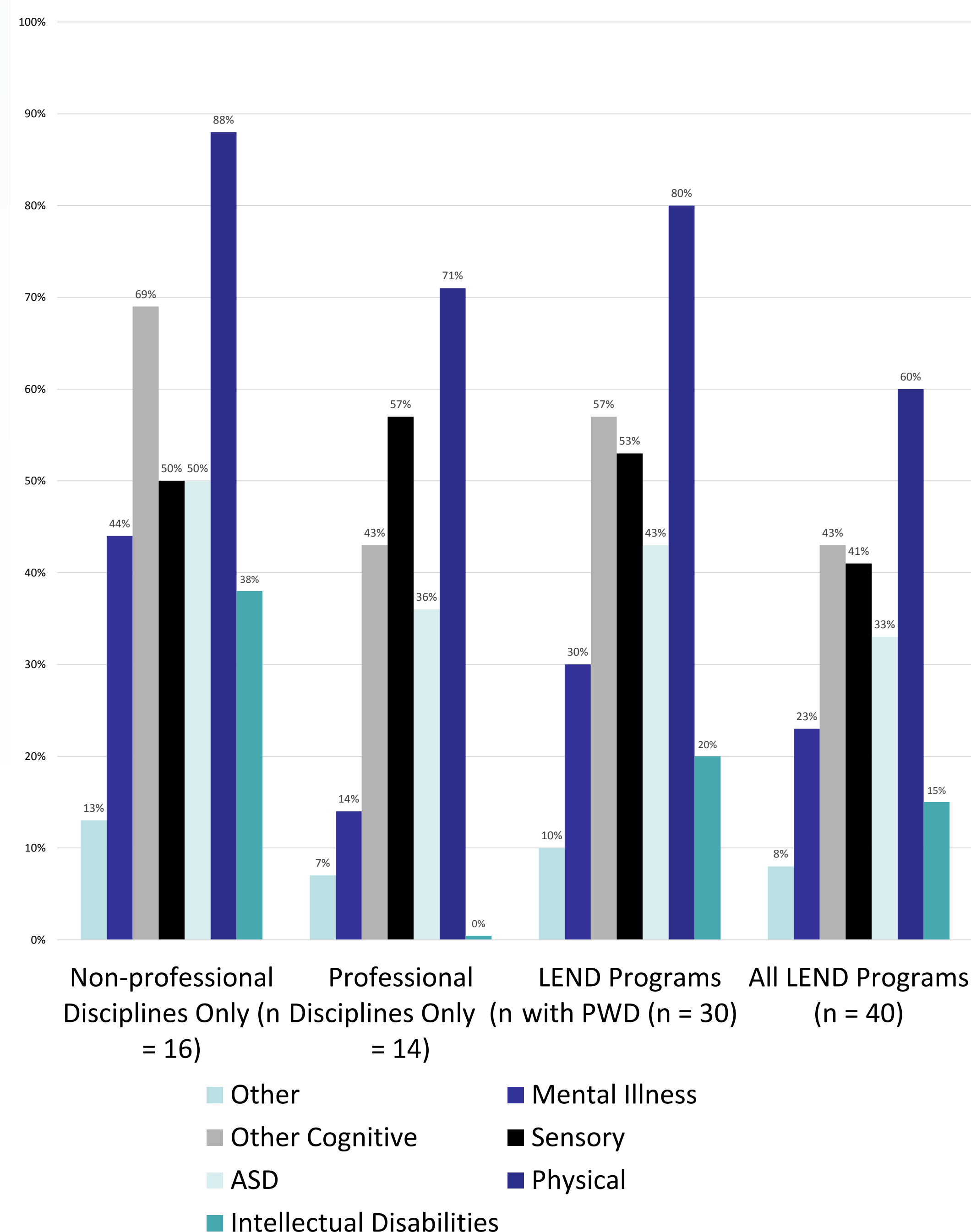
- 30 programs (70%) have included PWD as LTT
- All of these programs have included PWD as LTT in professional disciplines
- 16 programs have included PWD as LTT in a non-professional discipline (either family or advocate/self-advocate)

DISCIPLINES OF LONG-TERM TRAINEES WITH DISABILITIES



- PWD are enrolled in Professional Disciplines Only
- PWD are enrolled in Family Discipline Only
- PWD are enrolled in Advocate/Self-Advocate Discipline Only
- PWD are enrolled in both Family and Advocate/Self-Advocate Discipline

TYPES OF DISABILITIES REPRESENTED



PWD in Various LEND Roles

- All programs have involved PWD in some capacity
- PWD have served in a variety of different capacities

ROLE OF PEOPLE WITH DISABILITIES IN LEND PROGRAMS (N=40)

LEND or University faculty / staff	48%
Interdisciplinary team members or coordinators in clinical settings	31%
Community-based mentors to host LEND trainees for home or community visits	52%
Guest presenters or panelists who share their stories during LEND sessions	95%
Community-based LEND program advisors or consultants regarding clinical issues	55%
Community-based LEND program advisors for thesis / manuscript preparation or research / leadership projects	43%
Community-based members of an advisory council	74%
Participating in research	57%
Participating in program planning, implementation, and evaluation	64%

RECRUITMENT and PAYMENT OF LONG-TERM TRAINEES WITH DISABILITIES

- 80% of programs used some type of recruitment strategy. Most common strategies include referrals from community partners and former trainees.
- All of the programs reported majority of PWD LTT were compensated through stipends
- Programs with PWD in professional or family disciplines also reported other forms of compensation,

HOW DO THE TRAINING REQUIREMENTS/PARTICIPATION OF TRAINEES WITH IDD COMPARE TRAINEES FROM OTHER DISCIPLINES?

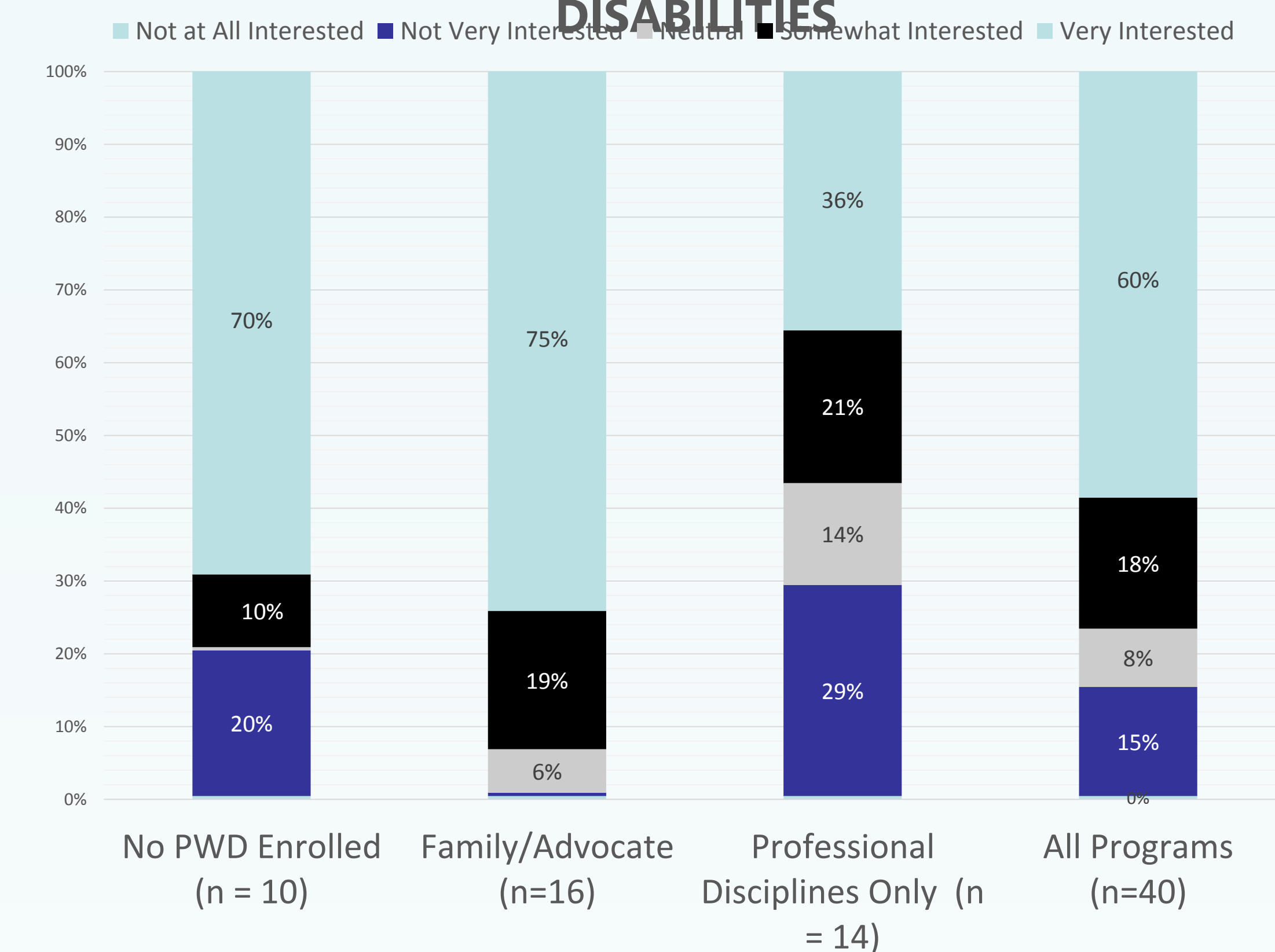
Activity/assignment type	% same
Didactics	90
In-class assignments	90
Policy Projects	87
Leadership Activities	87
Out of class assignments ⁺	80
Clinical sessions (74%) [*]	74

⁺ P<0.05 for out of class assignments vs didactics and in-class assignments

^{*} P<0.05 for clinical sessions vs didactics, in-class assignments, policy projects, and leadership activities

Program Interest

INTEREST IN DEVELOPING A DISTINCT DISCIPLINE FOR TRAINEES WITH DISABILITIES



Discussion

- PWD participate in a variety of roles across the network
- The majority of LEND programs responding have included PWD as long-term trainees, enrolled in professional and family/advocate (combined) disciplines fairly equally.
- As LEND trainees, PWD most commonly have physical disability, followed by other cognitive and sensory.
- There is significant interest (almost 80%) among LEND programs reporting to develop a distinct discipline for trainees with disabilities
- In order to develop a distinct discipline for trainees with disabilities, resources to overcome system barriers to inclusion need to be identified and disseminated.

Next steps

- Development of online repository of best practices/strategies that address common barriers
- Targeted TA and program to program mentorship for programs interested in expanding/establishing Self-Advocacy discipline
- Evaluate progress

Limitations

- Cross sectional data
- Self-report

Acknowledgements

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