

# The Purposeful Inclusion and Support of People with Disabilities in LEND Training

Challenges, Strategies, and Guidance

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## Preface

It has long been understood within the disability civil rights movement that people with disabilities, including those with intellectual and developmental disabilities, offer a unique and incredibly valuable perspective that is often unheard. Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs recognize the importance of having these individuals as trainees; when this occurs, training shifts from talking about people with disabilities to talking with them. While the majority of LEND programs include people with disabilities in some capacity within training, [recent data](#)<sup>1</sup> indicates that the level of participation varies greatly across the network.

Within their cohorts, trainees with disabilities practice leadership as they share their lived experiences with others, build connections, and serve as role models. They translate these skills and apply them beyond the classroom and into the community. Completing a long-term traineeship is an opportunity for a person with disabilities to expand their focus and understand how their personal advocacy fits within the scope of broader, systems level issues.

Including people with disabilities as trainees also enhances the leadership trajectories of other trainees. Hearing from these individuals as equals around the table encourages real connections, alters perceptions, and impacts how trainees will interact with and provide services and supports to people with disabilities throughout their professional careers.

The goal of this resource is to promote the purposeful inclusion and support of people with disabilities as long-term trainees in LEND programs by (1) identifying the primary challenges programs face across different areas, particularly related to implementation; (2) highlighting strategies that programs are successfully using to overcome these challenges; and (3) offering guidance that can help all programs move toward the achievement of this objective in a thoughtful and timely manner.

This resource is a product of the *LEND Workgroup on People with Disabilities as Long-Term Trainees*, a follow up to its 2014 survey on the state of participation among people with disabilities in LEND programs. All information was collected from LEND Directors and relevant faculty members in response to questions (sent via email in August 2015) about their programs' experiences engaging people with disabilities.

The document is organized into four topical sections, representing the primary challenges as identified by workgroup members:

- I. Faculty and Institutional Buy-In
- II. Trainee Recruitment
- III. Funding Availability and Flexibility
- IV. Curriculum Adaptation, Accommodations, and Mentorship

Each section includes a brief description of the challenge and its application in the LEND context, bulleted lists of strategies that programs are currently implementing to address that particular challenge, and themes that emerge from the experiences of successful programs. This document will be updated periodically, as more programs continue to embrace the shift toward full inclusion of people with disabilities in training.

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<sup>1</sup> Acharya, K., Holt, J., et al. (2015, November). *The Role of People with Disabilities in LEND Programs: Results of a National Survey*. Poster presented at the Association of University Centers on Disabilities 2015 Conference, Washington, DC. Accessed from <http://bit.ly/1Kbeqe1>.

## I. Faculty and Institutional Buy-In

Although there is general agreement among LEND faculty that people with disabilities add significant value to the training experience, building support for a specific discipline designation for individuals with disabilities can be a stumbling block to implementation. Some programs report hesitancy due to a perceived lack of available mentors, while others express concern that an individual with disabilities may not be adequately prepared for the rigors of a long-term traineeship that is designed for graduate students and future service professionals. Even the most supportive faculty may struggle to find time in their busy schedules to adjust didactic content and presentation style so that they are accessible to all trainees. University or institutional requirements (e.g. enrollment in a graduate or postdoctoral program as a prerequisite for receiving a stipend) can also make it challenging for programs and faculty to envision how having a trainee with disabilities would actually work.

### Strategies that address these challenges include:

- The LEND in North Carolina found that faculty members were more open to the idea of including people with disabilities when it was presented to them as an opportunity to expand diversity within the training cohort. Program leadership also presented it as an opportunity to make the program more consistent with their university's priorities, using the mission statement as a framework.
- Utah Regional LEND held open, honest discussions about the benefits and challenges with individual faculty members and during staff meetings; these were led by the Director and Family Discipline Coordinator and generated important questions (e.g. "How do we modify clinical requirements?") that helped the program create a rich learning experience.
- The LEND in Georgia eases faculty members' concerns about possible administrative burdens by allocating money in their annual budget for a graduate assistant; this individual helps faculty make their presentations and content accessible to all learners.
- The North Carolina LEND has also found it useful to draw on data, resources, and best practice information (e.g. adapting the Think College framework and benchmarks, found at [www.thinkcollege.net](http://www.thinkcollege.net)) that have been developed around postsecondary education for students with intellectual and developmental disabilities; this can help faculty understand that they don't need to "recreate the wheel" for a trainee with disabilities to be engaged in the curriculum.

Programs that have been successful understand the value of including people with disabilities in training and address the challenges up front. Most suggest that selecting the right candidate for this traineeship in the first year (and even including this potential individual in planning meetings with program leadership) makes a significant difference in terms of creating and sustaining buy-in over the long term. The more opportunities a trainee with disabilities has to interact in intimate settings with faculty and other trainees throughout the course of the year, the greater the likelihood that new champions for this inclusive approach will emerge. Directors can and should lead by example on this front.

## II. Trainee Recruitment

Even when there is faculty and institutional buy-in, programs still need to find ways to attract people with disabilities to the opportunity, including being able to clearly articulate why individuals might want to participate. Some programs report having trouble identifying appropriate candidates (requirements for consideration vary greatly) from within their networks. A few programs feel strongly that this should be an individual with at least some postsecondary

education, while others simply require that this candidate have public advocacy experience and clear goals for what they want to accomplish by participating in LEND training. State and regional self-advocacy groups can help inform recruitment practices and create a pool of potential trainees, but building those relationships often takes significant time and energy.

### Strategies that address these challenges include:

- Arizona LEND encourages faculty members to network with friends, acquaintances, and trusted organizational partners to help recruit potential trainees with disabilities.
- Illinois LEND recruits by tapping into the personal and professional networks of former trainees and reaching out to local chapters of organizations (e.g. [Self Advocates Becoming Empowered](#)) and community partners who employ people with disabilities. They have also found it helpful to create recruitment materials specifically for potential trainees with disabilities, including a video on the program's website that can also be sent via email and a separate plain language application.
- The LEND in Georgia applies the same recruitment philosophy for individuals with disabilities as they do for those applying from professional disciplines: "Just as we would not recruit a speech-language pathologist who did not view herself as a current or future leader, we are intentional about recruiting individuals with disabilities who view themselves as current or future leaders."
- Utah Regional LEND receives recruitment assistance from their state Developmental Disabilities (DD) Council, the disability resource centers at each of its participating universities, and faculty members who work with young adults.
- The North Carolina LEND found it helpful to establish a recruitment team that consists of key program personnel. In their case, this means the assistant director, director of advocacy initiatives, an individual with a disability who is a current trainee, and the education coach. This recruitment team reviews applications and conducts interviews to get a sense for each applicant's interest and level of motivation. They specifically seek out trainees with previous leadership experience (e.g. [Partners in Policymaking](#) graduate, Special Olympics Global Ambassador, former AmeriCorps member).
- Nisonger Center LEND (Ohio) recruits people with disabilities from community programs in which they are involved. More recently, they began partnering with their university's [Transition Options in Postsecondary Settings](#) (TOPS) program, which provides young adults with intellectual and developmental disabilities opportunities to engage in academic and work experiences while developing independent living skills and participating in campus life.

Programs that have been successful in recruiting trainees with disabilities have a process in place that leads to trainees who have the interest, commitment, and skills to take full advantage of the opportunity. The programs also have an understanding that like all LEND participants, people with disabilities apply to gain skills on their way to another step in their careers. While some may find LEND organically, recruitment success truly begins and ends with active faculty engagement (i.e. making it a priority) at all stages. This can mean anything from adjusting marketing strategies to directly appeal to this population; to arranging for potential candidates to visit with current trainees, attend seminars, and spend time with faculty before determining their "fit" with the program; to building a statewide network of groups that can support recruitment. Once a trainee with disabilities has gone through a program, he or she can inform future efforts.

## III. Funding Availability and Flexibility

People with disabilities are included as a group of trainees that can participate and be supported in LEND programs according to guidance from the Maternal and Child Health Bureau. However,

there are no clear expectations or guidelines for how these individuals are to be included in training, and institutional policies differ from one LEND program to another. For example, how do you classify someone in a university setting if he or she is not obtaining a graduate degree? In some cases, programs also need to figure out how to provide some form of compensation without disrupting a trainee's eligibility for Supplemental Security Insurance (SSI) or related benefits.

### Strategies that address these challenges include:

- Ohio's Nisonger Center LEND supports trainees with disabilities and their faculty mentors as independent consultants to their LEND grant; contracts are run through the university's Office of Sponsored Projects. A scope of work is written in a manner which allows for a flexible schedule (e.g. intermediate or long-term traineeship) based on an Individualized Learning Plan.
- The North Carolina LEND provides stipends to their trainees with disabilities, as well as support to review the potential impact of financial decisions. They have been able to create different payment schedules in instances when doing so would be helpful.
- Illinois LEND designates trainees with disabilities as hourly employees like other non-graduate student trainees. In cases when someone is unable to accept their stipend (which is the same amount for all trainees) because of implications to their benefits, the program has arranged for in-kind payments instead, such as covering conference registration and travel expenses.
- The Georgia LEND provides stipends to trainees with disabilities that are equal to those received by family trainees and masters-level community professionals, and all are eligible to apply for partial travel support to attend conferences.
- WIHD LEND in Westchester, New York, budgets in advance to have stipends for trainees with disabilities, plus a small amount of funding for supports (e.g. tutoring). They also refer trainees with disabilities to a benefits navigator to help determine how the stipend would fit in with benefits and other sources of income.

When it comes to paying trainees with disabilities, programs that have been successful find creative ways to leverage their existing framework. They also emphasize the importance of good working relationships with other institutional entities, such as sponsored programs offices or human resources departments. Staff understand the myriad of regulations associated with federal funding and the circumstances under which it can (and cannot) be used.

## IV. Curriculum Adaptation, Accommodations, and Mentorship

Because the majority of LEND curricula were designed for graduate-level trainees in health and related disciplines, adaptations are often necessary to ensure that trainees with disabilities can participate to the greatest possible extent. This, however, can be a delicate balancing act. While it is important to tailor the program to each trainee and provide supports to optimize learning, some have concerns that doing so has the potential to diminish the inclusive nature of the training experience. Some question whether having a trainee with disabilities could “dilute” the experience for others if he or she were to require a significant amount of time and attention, particularly if there is a difference in the level of formal education obtained. For trainees who are not part of a professional academic discipline, it can be challenging to determine the degree to which they should be engaged in the clinical components of the LEND curriculum. Programs also struggle when accommodations are determined to be cost-prohibitive (e.g. assistive technology) or otherwise unavailable. For example, a program recruiting its first trainee with disabilities may not have access to an appropriate mentor.



## Strategies that address the challenges of *curriculum adaptation and other accommodations* include:

- Nisonger Center LEND in Ohio has every trainee complete an individualized learning plan at the beginning of the academic year, which includes identifying specific supports needed. Trainees with disabilities are encouraged to arrive 15 minutes early to any scheduled LEND activity (especially didactic classes) to meet with faculty and preview the content which will be discussed. The program also requires that all trainees know how to use email prior to beginning the program.
- The LEND in North Carolina created a core course, *Developmental Disabilities Across the Lifespan*, that applies a problem-based learning approach. This format provides interactive learning opportunities that universally accommodate a range of learning strengths and styles. They also recruit an education coach to support trainees with disabilities with program activities as needed. It has traditionally been a psychology, special education, or occupational therapy student who takes this position (which includes faculty supervision and mentorship) as part of their trainee project experience. The education coach – whose role often fades as a trainee’s needs shift – may help review the week’s case and readings, formulate online discussion comments and responses, search for resources to include with an online post, or prepare for class by reinforcing learned concepts. This approach helps the program meet a critical support need without the need for a separate funding stream.
- The WIHD LEND in Westchester, New York, has all trainees with disabilities complete a needs assessment that addresses everything from academic assistance to how technology may be helpful. Laptops are available at all LEND sessions for trainees who cannot take notes with a writing implement, weekly one-hour prep sessions are held for trainees who require assistance with organizing and completing assignments, and have even structured one individual’s training plan around their target objective of obtaining competitive employment.
- The Utah Regional LEND and Illinois LEND allow trainees with disabilities to replace some or all of their clinical hours with other relevant activities, which is the same policy that is in place for trainees from all other non-clinical disciplines (e.g. public health, health administration, and business).
- Mailman Center LEND in Florida has considered having trainees with disabilities becoming involved in a quality improvement project in place of the clinical requirement.
- Illinois LEND created a [Self-Advocacy Discipline Manual<sup>2</sup>](#); this working document outlines nine competencies and suggested learning activities for each. Faculty meet individually with trainees with disabilities upon acceptance to the program to discuss and identify necessary supports related to didactics, clinical experiences, and other assignments. The Self-Advocacy Coordinator and faculty mentors conduct at least monthly check-ins to ensure that supports are adequate. They also have graduate assistants help trainees with disabilities on an as needed basis with anything from note taking and email to navigating the course’s online learning platform and preparing presentations. The program has found that peers are a natural source of support for trainees with disabilities and as a result, they have made it possible for all trainees to complete most assignments in groups.
- The LEND in Georgia makes it a point to teach and remind all of their expert presenters about including any necessary accommodations in their lectures and experiential activities.

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<sup>2</sup> Illinois LEND. (2014). *Self-Advocacy Discipline Competencies*. Accessed from <http://bit.ly/1P7oPQF>.

- Arizona LEND allows additional time for trainees with disabilities to complete their presentations and other required assignments, while Nisonger Center LEND in Ohio provides trainees with disabilities with increased access to faculty mentoring.

### Strategies that address challenges of *guidance and mentorship* include:

- The LEND in Georgia schedules regular mentorship meetings between trainees with disabilities and their discipline advisors, the same structure that is in place for family trainees. These meetings occur once per month and provide an opportunity for everyone to reflect on the relevance of the LEND curriculum for their discipline and to address any questions or concerns that arise.
- The LEND in North Carolina has two faculty members with expertise in special education, advocacy, and interactive learning provide mentoring to trainees with disabilities. This partnering approach has been helpful in identifying strategies to meet individual needs and provides continuity for mentoring the education coach as well.
- Utah Regional LEND has a Faculty Advocate (plus other core faculty) available for mentoring around content issues, and the Family Faculty member provides strong support as well. They have weekly contact at a minimum, helping prepare trainees with disabilities for seminars, debriefing activities, and ensuring that they are comfortable with the level of teamwork.
- The LEND in Washington established a “pod” to address isolation among trainees with disabilities and provide support. In addition to the first and second year trainees, the “pod” includes three other individuals: the Self-Advocate Faculty member, a Faculty Ally, and the Self-Advocacy Discipline Leader.
- Illinois LEND appoints a former trainee with disabilities as a Training Coordinator for current trainees. Like others in the program, trainees with disabilities meet at least monthly with their coordinator. Because that individual may need their own support, other faculty (project coordinator, clinical director, etc.) are available for guidance and mentorship and the trainee is informed about these opportunities at the start of the year.

Programs that have been successful in addressing challenges of including people with disabilities as trainees maintain open lines of communication regarding adaptations and accommodations throughout the academic year, and do so with self-direction and empowerment in mind. Trainees with disabilities may not volunteer information about their needs or feel comfortable seeking assistance, so faculty ask directed questions and try to normalize context. When programs start this process early and regularly check in with trainees, they find it easier to anticipate, identify, and address challenges that may require accommodation as they arise (e.g. before conferences or out of class activities) and make necessary adjustments. They also stress the importance of helping trainees move forward in each curriculum area in ways that are not only in sync with program expectations, but with the skills, interests, learning styles, and motivations of the individual. Mentorship is most effective when it is accessible, consistent, encouraging, and focused on helping trainees with disabilities use their LEND experience as a springboard for achieving personal and professional goals.