LEND Self-Advocacy Discipline Competencies

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INTERDISCIPLINARY TECHNICAL ASSISTANCE CENTER
ON AUTISM AND DEVELOPMENTAL DISABILITIES

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Introduction to the LEND Self-Advocacy Discipline Competencies

The LEND Self-Advocacy Discipline Competencies is a product of the LEND Self-Advocacy Discipline Network (LSDN), formerly known as the Purposeful Inclusion of People with Disabilities (PWD) Workgroup. Leadership Education in Neurodevelopmental and Related Disabilities (LEND) training programs must include individuals with disabilities as Self-Advocate trainees as a distinct discipline alongside graduate students, family members, and community trainees. Self-Advocates offer an invaluable perspective in the scope of the training: the lived experience of disability.

We hope this document guides your program as you support Self-Advocate trainees in their leadership journey.

Intended Audiences

The LEND Self-Advocacy Discipline Competencies are to be used by:

- LEND Project Directors/Training Directors
- LEND Self-Advocacy Faculty
- LEND Self-Advocacy Trainees

Purpose of the LEND Self-Advocacy Competencies

The purpose of LEND Self-Advocacy Discipline Competencies is to offer LEND training programs a set of tools to help Self-Advocate trainees individualize their leadership goals and learning plan during their participation in a LEND training program. Competencies describe the skills, knowledge, and behaviors that leaders have or will develop during their LEND training year.

The LEND Self-Advocacy Competencies are designed to add to the MCH Leadership Competencies and any other competencies the program wishes to use. They are not intended to form a separate curriculum for Self-Advocates; instead, they can be used as a guide and help spark ideas on how to meet the discipline-specific learning needs and personal leadership goals of a Self-Advocate trainee.

After completing the self-assessment, Self-Advocate Faculty members will help their trainees choose which competencies they want to focus on during their LEND year.

The suggested activities and resources may also be good tools for LEND Directors and Training Directors developing curricula for their program, or for other trainees in the program. The use of these competencies is not required by Health Resources and Services Administration (HRSA)/Maternal and Child Health Bureau (MCHB).

How to Use:

The LEND Self-Advocacy Discipline Competencies are organized into five areas:
1. Self-Advocacy
2. The Disability Civil Rights Movement (DCRM) and other Models of Disability
3. Advocacy and Policy
4. Disability Culture
5. Equity, Diversity, and Inclusion

Self-Assessment Tool
Trainees begin the LEND program with knowledge and skills in some competency areas. A competency area describes the skills, knowledge, and behaviors that leaders have or will develop during their LEND training year. The self-assessment tool (Appendix 5) is a survey that trainees will complete about themselves. It helps trainees understand what they know and what they want to learn in each area. This tool will help the trainees write their learning plan and leadership goals.

Suggested steps for using this document
- Trainee completes the self-assessment tool before they begin LEND. This will assist the Self-Advocate Faculty and trainee in learning about the trainee's strengths, areas of growth and what they would like to learn about during LEND.
- Provide your trainee with a copy of the competencies and their self-assessment (the Self-Advocate Faculty keeps a copy).
- Review the five (5) competency areas with your trainee.
- Decide with your trainee which competencies they would like to focus on.
- Use the learning plan included in each competency to pick learning objectives your trainee would like to work on during LEND. Each learning objective has possible activities for your trainee to complete.
- The learning plan has an area for note-taking and links to videos, pictures, and websites that will help your trainee during the learning process.
- Trainee completes the self-assessment again at the end of LEND**.**
- Review areas of growth, successes, and next steps with the trainee.

1: Self-Advocacy

Definition

Self-Advocacy is knowing your rights, as a person with a disability, and speaking up for what you need and what you want. Self-Advocacy can help someone become self-determined, which means they have control over their life.

Knowledge Areas

Self-Advocates will know the following:

1. The skills, ideas, and actions of strong Self-Advocates.
2. That they can make decisions about their own lives.
3. That their experiences are valuable and need to be shared to make change.

Learning Plan

Learning Objectives	Recommended Activities
1. Improve Self-Advocacy Skills	☐ Interview a Self-Advocate leader in your community. ☐ Practice using Self-Advocacy skills in a meeting.
2. Talk about how Self-Advocacy leads to Self-Determination	☐ Give examples of when you advocated for yourself. • Have a conversation with your Self-Advocate faculty about your plans during and after LEND related to advocating for yourself and others with disabilities.

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Recommended Resources

*Lydia X. Z. Brown: Self-Advocacy and Beyond. Interviews with Leaders of the Self-Advocacy Movement [Learning Objective 1]
https://www.youtube.com/watch?v=_NB55O0wevUc
This video is presented by SARTAC (Self Advocacy Resource and Technical Assistance Center). Tia Nelis interviews Lydia X. Z. Brown, a lawyer, advocate, organizer, and writer whose work has focused on violence against people with disabilities in schools, institutions (a place where people with disabilities are sometimes sent to live), prisons, and by police. Lydia advocates for disabled people at many margins, including people of color and Lesbian, Gay, Bisexual, Transgender, and Queer(LGBTQ+) people with disabilities. This video is 19 minutes, 14 seconds long.

* Tia Nelis: Self-Advocacy and Beyond. Interviews with Leaders of the Self-Advocacy Movement [Learning Objective 1]
https://www.youtube.com/watch?v=kyQ2JLo2Koo
Nancy Ward interviews Tia Nelis, the first LEND Self-Advocate trainee about Self Advocacy. This video is 8 minutes, 34 seconds long.

*Self Determination Channel [Learning Objective 1]
https://www.youtube.com/channel/UCgSBRbXjC_IoiTS92fjGvxA
Self-Advocates host the Self-Determination Channel and choose the content. Trainees can pick from many different topics. The site includes videos with audio descriptions.   The videos are between 7 to 9 minutes.

*Self-Advocacy [Learning Objective 1]
https://www.youtube.com/watch?v=fCjwA67THIc
This video contains 5 steps that will help you learn to be a Self-Advocate. This video 3 minutes, 3 minutes long.

*Green Mountain Self Advocates on Self-Determination [Learning Objective 2]
https://youtu.be/uwDvkinIIDw
Max Burrows interviews people with developmental disabilities from Green Mountain Self-Advocates about Self-Advocacy and Self-Determination. This video is 3 minutes, 28 seconds long.

2: Disability Civil Rights Movement (DCRM) & Other Models of Disability

Definition

The **DCRM** started when people with disabilities began to advocate for equal rights in the United States. It was Inspired by the American Civil Rights Movement, a group advocating for the equality of Black Americans since the 1950s. "Nothing About Us Without Us" is a motto of the DCRM.

A **Model of Disability** is a description of how or why disability is the way it is. It effects how people with disabilities are talked about and treated in their community. The two most common models of disability are the social model and the medical model.

Knowledge Areas

Self-Advocates will know the following:

1. The way the DCRM has changed the lives of people with disabilities for the better
2. The different Models of Disability and how they are used by the community
3. How the DCRM and Models of Disability are connected

Learning Plan

Learning Objectives	Recommended Activities
1. Explain the Disability Civil Rights Movement	☐ Watch *Crip Camp* and talk about the video with other trainees. ☐ Name important and well-known disability civil rights leaders and describe their leadership styles. ☐ Look up national and state laws that protect people with disabilities.
2. Identify the major Models of Disability	☐ Provide examples of the Medical, Moral, and Social Models of Disability. ☐ Watch Social Model Animation Video (listed below in Recommended Resources).

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<u>**Recommended Resources**</u>

*ADA Guideline of Disability Civil Rights Laws [Learning Objective 1]
https://www.ada.gov/cguide.htm
This website provides information on many of the disability rights laws. It was updated in 2020.

*2 Disability Rights Activists on the Power of the ADA—And Where it Falls Short [Learning Objective 1]
https://www.youtube.com/watch?v=8UWexN1C1cc
An interview with disability civil rights activists Judy Heumann, previously a special advisor to the United States State Department, and Keri Gray of the American Association of People with Disabilities on the 30th anniversary of the Americans with Disabilities Act (ADA.) This video is 8 minutes, 5 seconds long.

*A Brief History of the Disability Rights Movement [Learning Objective 1 and 2]
https://www.youtube.com/watch?v=cNYhFDpAHtk
This video covers the Moral, Medical, and Social Models of Disability. The speaker talks quickly, but the audio can be slowed down if needed. This video is 14 minutes, 13 seconds long.

*Models of Disability: Types and Definitions [Learning Objective 2]
https://www.disabled-world.com/definitions/disability-models.php
Article: This website describes the different Models of Disability. In addition to the Social and Medical Models, this site introduces readers to other Models of Disability that are less commonly talked about. This resource can be used by Self-Advocate Faculty Members to lead a conversation with trainees about the different ways disability is discussed within the United States and world.

*Social Model Animation [Learning Objective 2]
https://www.youtube.com/watch?v=4liF-zuwGxE
An animated video about what it would be like if our society was created around people with disabilities instead of non-disabled people. This video is 1 minute, 26 seconds long.

3: Advocacy & Policy

Definition
- **Advocacy**: knowing your rights, as a person with a disability, and speaking up for yourself and others
- **Policy**: the plans or goals used by a government, business or individual.
- **Law:** a rule that people in a country or a state have agreed is important to follow. There are laws about many things, like how fast to drive. People use laws to decide what is right and wrong.

Helpful Vocabulary
- **Medicaid:** A partnership between the federal government and your state to provide to health insurance and services.
- **Home and Community Based Services:** Integrated services provided to people with Medicaid, so that they are able to live in their own home or community instead of an institution.
- **Institution:** A facility or home that is separate from one's community and loved ones. In the past, people with disabilities were sent to live in these spaces without their input.
- **Campaign:** An opportunity to join your voices with others about an issue you care about.

Knowledge Areas

Self-Advocates will know the following:

1. How decisions made by leaders in organizations and governments impact the lives of people with disabilities
2. How to network or connect with others to make your voices heard
3. The importance of sharing lived experience with leaders to make change that benefits people with disabilities

Learning Plan

Learning Objectives	Recommended Activities
1. How decisions made by leaders in organizations and governments impact the lives of people with disabilities	☐ Research your state's policies and laws on disability, ex. Medicaid expansion and Home and Community Based Services (HCBS). ☐ Share about a policy or law that has impacted your life (school, employment, etc.).

2. Explain advocacy on a systems level (policy, legislation, wider community)	☐ Watch *Tuesdays with Liz* (listed below in Recommended Resources). ☐ Attend or watch a state legislative session. ☐ Look up local, state, and national advocacy groups. ☐ Attend a state or national policy conference. ☐ Set up a meeting with a representative, senator, or policy leader. ☐ Connect to an advocacy organization of your choice and follow them on social media. ☐ Participate in an advocacy campaign.
3. Understand how to network or connect with others	☐ Attend a networking event with your Self-Advocate faculty member. ☐ Attend a local disability advocacy group meeting to practice networking. ☐ Attend AUCD's SAIL peer group.

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Recommended Resources

*__Resources for States/Medicaid__ [Learning Objective 1]
https://www.medicaid.gov/resources-for-states/index.html

This site has website links for all the states' Medicaid programs. You can access the documentation for their State Plan for Medicaid and Medicaid Waivers. This is an advanced source.

*Plain Language: Medicaid Services for People with Intellectual and Developmental Disabilities – Evolution of Addressing Service Needs and Preferences [Learning Objective 1]
https://www.aucd.org/docs/publications/policy/PlainLanguageMedicaidServicesforPeoplewithIntellectualorDevelopmentalDisabilities.pdf
A report created by AUCD that discusses Medicaid services and supports for individuals with intellectual disabilities.

* People First of Nebraska Shows How to Contact Your Senator [Learning Objective 2]
https://www.youtube.com/watch?v=ad8s3IbSR6o
Adriana David, People First of Nebraska's Disability Policy Specialist, learns how she can call and request a meeting with her Senator. This video is 9 minutes, 22 seconds long.

*National Council of State Legislatures [Learning Objective 2]
https://www.ncsl.org/research/about-state-legislatures/legislative-webcasts-and-broadcasts.aspx
This site shows website links to state legislature floor debates and live broadcasts of hearings. It is an excellent opportunity to watch policymakers at the legislative level deciding on bills and listening to the public.

*Tuesdays with Liz [Learning Objective 2]
https://www.youtube.com/channel/UCmrnZuVCOOwe5DIAGbXoQdQ
Tuesdays with Liz: Disability Policy for all #policy4all. Liz Weintraub is a disability advocate, who works at AUCD. She interviews leaders on issues in disability policy in partnership with AUCD. Time varies.

*Policy Terms in Plain Language [Learning Objectives 1, 2, 3]
https://www.aucd.org/docs/Policy%20Terms%20in%20Plain%20Language_AUCD_5.2021.pdf
A document created by AUCD that includes definitions of common terms used in policy discussions.

4: Disability Culture

Definition

Disability culture is a set of behaviors, beliefs, and shared experiences of people with disabilities. Disability culture is a source of pride for many people with disabilities, as it represents a shared history of oppression and resilience. Throughout history, people with disabilities have unfortunately often been looked down upon or seen as less than people without disabilities. This has not stopped people with disabilities from rising up, speaking out, and reaching their goals.

Knowledge Areas

Self-Advocates will know the following:

1. The importance of disability culture
2. The definition of ableism which is discrimination against people with disabilities
3. How ableism leads to few opportunities for people with disabilities in the areas of health, employment, housing, etc.

Learning Plan

Learning Objectives	Recommended Activities
1. Understand what makes up disability culture	☐ Provide examples of representation of people with disabilities in movies, TV, books, music, entertainment, and the news. ☐ Have a conversation with your Self-Advocate Faculty member about your identity as a disabled person/person with a disability. ☐ Have a conversation about your other identities, such as race, ethnicity, gender, sexual orientation and where you are from.
2. Define & explain the concept of ableism	☐ Give an example of ableism in health, work, or education. ☐ Discuss strategies for responding to ableism.

3. Explain how ableism affects people with disabilities	☐ Talk about the concept of internalized ableism, which is when people with disabilities begin to accept negative ideas about themselves based on their disability.

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Recommended Resources

*Pursuit of a More Equitable World: Disability Culture & Society (John Kemp Talk #2, Audio Described) [Learning Objective 1]
https://www.youtube.com/watch?v=AVRjbY0DhQQ
In this video, John Kemp delivers a speech at the University of Washington. Mr. Kemp is one of America's leading advocates for people with disabilities. This video is 15 minutes, 37 seconds long. It is also available without audio description:
https://youtu.be/SCAhGhuWBgM

*What do you know about disability cultural competence? [Learning Objective 1]
https://swhelper.org/2021/11/19/what-do-you-know-about-disability-cultural-competence/
Dr. Elspeth Slayter, a professor of social work at Salem State University, in Salem, Massachusetts, discusses the importance of acknowledging that people need to understand that disability is a cultural group that deserves attention.

*Deaf History and Culture in the United States [Learning Objective 1]
https://vpm.org/articles/21368/deaf-history-and-culture-in-the-united-states
This is an article is an introduction to Deaf culture and the Deaf community. Deaf culture is known for visual language and disability pride.

*Independent Living Institute Newsletter on Disability Culture [Learning Objective 1]
https://www.independentliving.org/newsletter/12-01.html
This newsletter provides several articles on disability culture. It describes a group identity with a common history of oppression and a bond of resilience. People with disabilities generate art, music, literature, and other expressions of our life and culture, infused by the experience of disability.

*Ableism 101 [Learning Objective 3]
https://www.accessliving.org/newsroom/blog/ableism-101/
An article written by Ashley Eisenmenger that explains what ableism is and how to stop it.

Disability Visibility Project [Learning Objective 1, 2, 3]
https://disabilityvisibilityproject.com/
The Disability Visibility Project's website describes the project as "an online community dedicated to creating, sharing, and amplifying disability media and culture." This website provides examples of disability in media and entertainment.

5: Diversity, Equity & Inclusion (DEI)

Definition

"Diversity, Equity and Inclusion (DEI)" is described as policies and programs that focus on the inclusion and fair treatment of different groups of individuals, including people of different ages, races and ethnicities, abilities and disabilities, genders, religions, cultures, and sexual orientations.

Knowledge Areas

Self-Advocates will know the following:

1. Why it's important for disability to be included in DEI
2. That people with disabilities can be part of more than one unrepresented or underrepresented group.
3. That intersectionality is an idea that explains how a person's many identities can combine to either help the individual succeed or lessen their chances of success
4. The difference between equality, equity, and justice

Helpful Vocabulary
- **Equality:** Everyone having the same rights and access to opportunities.
- **Equity:** When someone receives the supports they need to participate in an opportunity. ("It levels the playing field.")
- **Justice:** The quality of making fair decisions.
- **Unrepresented:** When an individual or group is missing.
- **Underrepresented:** When there is only a few members of a group present or included.
- **Marginalized:** When people or groups are not included or heard within conversations.

Learning Plan

Learning Objectives	Recommended Activities
1. Understand DEI initiatives, including what they are, why they are important, and how disability factors in	☐ Attend/join DEI committee meetings at your workplace or LEND organization. ☐ Find examples of businesses in your community that consider disability a part of their DEI programs.

2. Define intersectionality and understand how disability intersects with other unrepresented groups.	☐ Find statistics that show the disability rates within other marginalized groups. ☐ In addition to disability, identify underrepresented groups and list ways they have traditionally been excluded. ☐ Watch: WeThe15 | Short Campaign Video (1 minute, 50 seconds)
3. Define equality, equity, and justice and understand how they are different.	☐ Discuss the infographic (cartoon with fence) on equity and equality with your mentor. [See first resource under Recommended Resources below] ☐ Share examples of supports you use that demonstrate equity. ☐Watch: Social Justice: What's disability got to do with it? (5 minutes, 18 seconds).

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RECOMMENDED RESOURCES

*3 Mistakes to Avoid When Including Disability In Your DEI Programs [Learning Objectives 1 and 2]
https://www.forbes.com/sites/andrewpulrang/2021/08/27/3-mistakes-to-avoid-when-including-disability-in-your-dei-programs/?sh=533f56c929aa
This article about including disability in DEI programs includes audio (11:03). Forbes requires a subscription if you access more than four (4) free articles.

*There's equality, equity … and then there's justice [Learning Objectives 1, 2, and 3]
https://news.asante.org/theres-equality-equity-and-then-theres-justice/
This article reviews the concepts of equality, equity, and justice.

*Impact: Feature Issue on Self-Advocacy for People with Intellectual, Developmental and Other Disabilities. [Learning Objectives 1, 2, and 3]
https://publications.ici.umn.edu/impact/33-1/cover

This issue of Impact explores the history of the Self-Advocacy Movement, including its shared history with the Civil Rights and Feminist movements of the 1960s and '70s. Self-Advocates share their thoughts about ableism and the multiplying effects when it combines with racism. Articles are in plain language and include an audio version.

*There Is No Justice That Neglects Disability [Learning Objectives 2]
https://ssir.org/articles/entry/there_is_no_justice_that_neglects_disability#
This article comments on the need for disability to be included in EDI initiatives. The authors describe the intersectionality approach and provide asy-to-read statistics.

*#WeThe15 [Learning Objectives 2]
https://www.wethe15.org/
This coalition of sports, human rights, policy, communications, business, arts, and entertainment organizations places persons with disabilities at the heart of the diversity and inclusion agenda.

Appendix 1: Acronyms

AUCD – Association of University Centers on Disabilities

DCRM - The Disability Civil Rights Movement

EDI –Equity, Diversity, and Inclusion

EDI Hub – Equity, Diversity, and Inclusion Hub

HCBS – Home and Community Based Services

LEND – Leadership Education in Neurodevelopmental and Related Disabilities

LSDN – LEND Self-Advocacy Discipline Network

MCH – Maternal and Child Health

MCHB– Maternal Child and Health Bureau

PWD – People with Disabilities

SA - Self-Advocacy

SAIL – Self-Advocates in LEND

Appendix 2: Additional Resources

For additional resources, please visit:

Excel - [LSDN Self-Advocacy Discipline Competencies Resource List](#)

PDF – [LSDN Self-Advocacy Discipline Competencies Resource List](#)

Please note: Excel may try to block the file as corrupted-click yes to continue download.

Appendix 3: Facilitated Discussion Guide

Before LEND

1. What strengths do you bring to the LEND cohort?

2. What would you like to learn about YOURSELF this year? What would you like to learn about ADVOCACY and LEADERSHIP this year? Why are these things important to you?

3. What do you hope to gain from this experience?

4. What would you like to be able to do when you've finished LEND?

5. Tell me about a time that you felt successful when learning something new. What about the experience helped you be successful?

After LEND

1. What strengths did you use during your LEND experience?

2. What did you learn about YOURSELF this year? What did you learn about ADVOCACY and LEADERSHIP this year? How will you use these things as a leader/advocate in the future?

3. What did you gain from this experience?

4. Did you do anything this year that you're proud of in LEND? Why are your proud of this moment?

5. Did you feel successful during LEND? Were you able to access the information in a way that was helpful to you? If no, what would have been better?

Appendix 4: References

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Appendix 5: Self-Assessment: Self-Advocacy Competency Scale

Trainee Name:_____Start Date: _____End Date: _____

At the beginning of your training (Pre), CIRCLE the NUMBER that reflects your knowledge And then again at the END (Post) of your LEND training.		I do not know how to do this	I am beginning to do this	I can do this	I can do this most of the time	I can always do this
Competency 1: I am self-determined.	Pre	1	2	3	4	5
	Post	1	2	3	4	5
Competency 1: I advocate for myself.	Pre	1	2	3	4	5
	Post	1	2	3	4	5
Competency 1: I advocate for others and the disability community.	Pre	1	2	3	4	5
	Post	1	2	3	4	5
Competency 2: I can explain what the disability civil rights movement is.	Pre	1	2	3	4	5
	Post	1	2	3	4	5
Competency 2: I can list important events, policies/laws, and people related to the disability civil rights movement.	Pre	1	2	3	4	5
	Post	1	2	3	4	5

		I do not know how to do this	I am beginning to do this	I can do this	I can do this most of the time	I can always do this
Competency 2: I can tell someone how the models of disabilities were shaped by the disability civil rights movement.	Pre	1	2	3	4	5
	Post	1	2	3	4	5
Competency 3: I can identify my state's systems of care.	Pre	1	2	3	4	5
	Post	1	2	3	4	5
Competency 3: I can explain how advocacy and policy are connected.	Pre	1	2	3	4	5
	Post	1	2	3	4	5
Competency 3: I can connect with policy makers to advocate for policy changes.	Pre	1	2	3	4	5
	Post	1	2	3	4	5
Competency 4: I can confidently identify as a person with a disability and feel connected to the disability community.	Pre	1	2	3	4	5
	Post	1	2	3	4	5
Competency 4: I can define ableism.	Pre	1	2	3	4	5
	Post	1	2	3	4	5

		I do not know how to do this	I am beginning to do this	I can do this	I can do this most of the time	I can always do this
Competency 4: I can recognize ableism when it comes in everyday interactions.	Pre	1	2	3	4	5
	Post	1	2	3	4	5
Competency 4: I can work with other advocates to explain the importance of including people with disabilities in spaces where people are making choices about our lives.	Pre	1	2	3	4	5
	Post	1	2	3	4	5
Competency 5: I can identify the various groups that I am a part of.	Pre	1	2	3	4	5
	Post	1	2	3	4	5
Competency 5: I can explain intersectionality and how it impacts access to opportunities.	Pre	1	2	3	4	5
	Post	1	2	3	4	5
Competency 5: I can recognize when disability is missing from conversations about policies/law that impact people like me and my peers.	Pre	1	2	3	4	5
	Post	1	2	3	4	5

Additional Supports for the Trainee (If desired):

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