

Intellectual and Developmental Disabilities

Inclusion in an Interdisciplinary Leadership Training Program: Perspectives from Self-Advocates

--Manuscript Draft--

Manuscript Number:	IDD-D-22-00064R2
Article Type:	Research
Keywords:	Interdisciplinary training, disabilities, self-advocacy, inclusion
Corresponding Author:	Allison P. Wayne, M.Ed. Georgia State University Atlanta, GA UNITED STATES
First Author:	Allison P. Wayne, M.Ed.
Order of Authors:	Allison P. Wayne, M.Ed.
	Andrew T Roach, Ph.D.
	Krysta LaMotte, M.Ed.
	Mark Crenshaw, MTS
	Emily Graybill, Ph.D.
Manuscript Region of Origin:	UNITED STATES
Abstract:	LEND programs are interdisciplinary, graduate-level training programs that seek to promote improved outcomes for individuals with disabilities and their families. Many of these programs include individuals with disabilities as members of the self-advocacy discipline. In this study, 10 self-advocate trainees were interviewed to provide insight into the value of including self-advocates in training and the kinds of accommodations and supports that facilitated their success and inclusion. Interviewees endorsed the importance of including self-advocates in LEND programs. While several accommodations were discussed as helpful, interpersonal supports from faculty and peers were equally important in ensuring their success and inclusion in LEND. The findings from this study provide support for the expansion of self-advocacy as a formal discipline in LEND programs.

Abstract

LEND programs are interdisciplinary, graduate-level training programs that seek to promote improved outcomes for individuals with disabilities and their families. Many of these programs include individuals with disabilities as members of the self-advocacy discipline. In this study, 10 self-advocate trainees were interviewed to provide insight into the value of including self-advocates in training and the kinds of accommodations and supports that facilitated their success and inclusion. Interviewees endorsed the importance of including self-advocates in LEND programs. While several accommodations were discussed as helpful, interpersonal supports from faculty and peers were equally important in ensuring their success and inclusion in LEND. The findings from this study provide support for the expansion of self-advocacy as a formal discipline in LEND programs.

Inclusion in an Interdisciplinary Leadership Training Program: Perspectives from Self-Advocates

Individuals with disabilities have historically experienced many social and educational inequities, including limited options to engage in postsecondary education and professional preparation programs. Recent policy initiatives have sought to address these inequities by increasing access and opportunities for individuals with disabilities in higher education. For example, the Higher Education Opportunity Act (HEOA) of 2008 supported the inclusion of individuals with intellectual and developmental disabilities (IDD) in higher education through federal funding intended to expand postsecondary educational options for these individuals (Madaus et al., 2012). While access to undergraduate or certificate educational opportunities has increased as a result of the HEOA, individuals with disabilities remain vastly underrepresented in graduate education. However, some graduate-level training programs are expanding to include individuals with disabilities. One example of such training programs is the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs, which provide interdisciplinary leadership training to a diverse group of trainees, including individuals with disabilities.

Leadership Education in Neurodevelopmental and Related Disabilities

The LEND programs are members of a national network that provides interdisciplinary leadership training to community members and professionals who work in disability-related fields. The goal of these programs is to improve health and life outcomes for people with disabilities by training current and future leaders to provide culturally competent, person-centered care. There are currently 60 LEND programs across the United States and its territories. These programs are funded by the Health Resources and Services Administration (HRSA),

operated by the Maternal and Child Health Bureau (MCHB), and receive technical assistance from the Association of University Centers on Disabilities (AUCD). While all LEND programs focus on interdisciplinary leadership training, each program is unique across many dimensions, including training models and range of trainee disciplines included.

Some LEND programs, like the Georgia LEND (GaLEND) program, recognize self-advocacy as one of the core trainee disciplines, including individuals with disabilities in all components of the program from coursework to policy activities. Recent initiatives by MCHB endorsed the expansion of the self-advocacy discipline to all LEND programs (Association of University Centers on Disability, n.d.). For instance, LEND programs funded during the current 5-year funding cycle are required to expand the representation of self-advocate trainees in their programs by the beginning of the 2023-2024 training year. According to MCHB's most recent notice for funding opportunities for LEND programs (HRSA-21-041), the self-advocacy discipline includes individuals with disabilities (including but not limited to IDD) who demonstrate a readiness to develop leadership skills and share their perspectives with fellow trainees. There is no educational prerequisite for LEND participation nor is there a requirement for active enrollment in other university training programs while participating in a LEND program as a self-advocate trainee. Thus, self-advocate trainees may be any individual with a disability who displays leadership potential and a willingness to discuss their lived experience with other trainees. In addition, LEND programs differ greatly in the credentials awarded following training. Some LEND programs offer a formal university-level certificate following the completion of program requirements, while others provide more informal certification or recognition. Regardless, LEND programs offer opportunities for developing a wide range of

professional and interpersonal skills and networking opportunities within the larger AUCD network.

To date, the existing literature on including non-traditional trainees, such as family members and self-advocates, in LEND training programs has focused on the perspectives of and benefits to traditional trainees who come from professional disciplines. Although there is an urgent need to better understand the perspectives and benefits to self-advocate trainees themselves, available research clearly documents benefits of including these trainees from the perspective of other trainees. For example, interdisciplinary training broadly benefits trainees from professional disciplines through enhanced communication skills, improved understanding of other professions, and increased collaboration and family-centered care practices in future practice (Rosenberg et al., 2015). Furthermore, interdisciplinary training that included the perspectives of families of children with disabilities has been viewed as promoting trainees' engagement in family-centered care practices as well as their understanding of the "lived experience" of disability (Graybill et al., 2016; Keisling et al., 2017; Vargas et al., 2012).

Expanding interdisciplinary representation by including self-advocates in training offers a similar opportunity to further enhance professionals' understanding of their roles in providing person-centered care and collaborating with people with disabilities to promote improved outcomes. The lack of representation of the self-advocate voice in LEND evaluation studies prevents faculty and staff from understanding the positive impacts that these training programs have for self-advocate trainees. Furthermore, self-advocate perspectives on the supports that promote their success are essential in better understanding how to increase their meaningful participation in LEND programs.

Accommodations for Self-Advocate Trainees

To promote meaningful inclusion, it is important that LEND programs understand the accommodation and support needs for self-advocate trainees. The current research literature on accommodations in LEND programs is limited. Graybill and colleagues (2020) conducted a case study in which they highlighted the accommodations provided in the GaLEND program. In this study, the self-advocate trainee who participated indicated they received course content in advance of lectures and that content was occasionally modified to meet their learning needs when the need arose. In addition, interpersonal supports were provided by many individuals, including a peer learning partner, faculty, and guest lecturers. Conversations about the necessary accommodations process were often initiated by faculty, who prioritized providing the trainee with the appropriate supports to ensure their success and inclusion in all aspects of the program.

While the literature on providing accommodations in LEND programs is extremely limited, there is more research on accommodating students with disabilities in postsecondary educational settings broadly. Accommodations in postsecondary education seek to reduce barriers that diminish access to educational opportunities for individuals with disabilities without reducing or altering learning expectations and objectives (Katsiyannis et al., 2009). Although the purpose of accommodations is to facilitate access, individuals with disabilities often experience unique barriers in postsecondary education. For example, requesting accommodations generally requires students to self-disclose their disability status and engage in self-advocacy to request needed supports. Unfortunately, some students with disabilities may not have developed the necessary skills or knowledge to effectively advocate for their educational needs (Garrison-Wade, 2012; Kutscher & Tuckwiller, 2019; Summers et al., 2014). Further, students with disabilities sometimes encounter negative interactions with faculty who appear unable or

unwilling to accommodate their learning needs, exacerbating barriers to access and inclusion (Cawthon & Cole, 2010; Lindsay et al., 2018a).

In most cases, effective accommodation planning can help students with disabilities succeed in postsecondary educational settings. Supporting students with disabilities in postsecondary education involves personalized accommodation planning that considers students' unique needs and strengths, rather than prescribing the same accommodation to all individuals with a disability (Dunn et al., 1994). Further, effective accommodation planning processes empower students with disabilities to take the lead in planning for their success (Ryan & Griffiths, 2015). Allowing students to participate in accommodation planning and identify the most useful supports can facilitate subsequent accommodation use (Abreu et al., 2016). Faculty and staff can support students in enhancing their self-advocacy skills by intentionally creating spaces for discussing their learning needs and preferences (Garrison-Wade, 2012).

Purpose

The purpose of this study is to examine the experiences of self-advocate trainees in the GaLEND program. Specifically, the researchers were interested in capturing self-advocate trainees' perceptions about the importance of including trainees with disabilities in interdisciplinary training programs. Our data collection and analyses sought to address the following research questions:

1. What are the benefits of including self-advocate trainees in the GaLEND program?
2. How have accommodations provided by the GaLEND program enabled self-advocate trainees to access curriculum in ways that meet their learning needs?
3. What supports may be helpful for promoting the success and inclusion of future self-advocate trainees in LEND programs?

Method

Participants

Purposeful sampling was used to examine the experiences of former GaLEND trainees. Participants were self-advocate trainees who had completed the GaLEND program from the years 2011-2021. Prior to admission to GaLEND, self-advocate trainees shared information about their disability with GaLEND faculty, some of whom were members of the research team. Thus, information about the disability status of potential participants was known prior to recruitment. The potential participants represented a wide range of disabilities, including various neurodevelopmental disabilities and IDD (see Table 1). Thirteen potential participants were sent a recruitment email with information about the study and accessible consent forms. Ten individuals agreed to meet to discuss the research project and consent forms. Prior to meeting with potential participants, the research team offered to provide any necessary accommodations during the interview process. No participants requested specific accommodations as part of their participation. A research team member met with each participant via Webex to provide information about the study and explain the content of the consent forms in plain language prior to obtaining their consent for participation. Webex offered captioning services that could be enabled by participants at any time. No incentives were offered for participation in this study.

INSERT TABLE 1 ABOUT HERE

Data Collection

Individual semi-structured interviews were conducted to investigate the experiences of self-advocate trainees in the GaLEND program. Interview questions focused on a variety of topics related to participants' experiences in GaLEND, including accommodations and supports, the value and importance of self-advocate representation in the trainee cohort, and suggestions

for future improvement to promote future self-advocate trainee success and inclusion in GaLEND. The GaLEND evaluation team collaborated to design the initial interview protocol based on agreed-upon evaluation needs. In addition, interview questions were piloted with two former self-advocate GaLEND trainees who were not included as participants in this study. This enabled the research team to discuss the appropriateness of questions and make any necessary modifications. Piloting also revealed need to define terms in plain language. Thus, a glossary of terms was created to ensure certain terms (e.g., discipline, accommodations) were defined in accessible language. The interview protocol (see Figure 1) used for this study included seven core questions. Additional follow-up questions and prompts were developed and used to elicit more detail or elaboration on participant responses.

INSERT FIGURE 1 ABOUT HERE

The same research team member who facilitated the informed consent process, also conducted each of the interviews using the Webex online meeting platform. This interviewer had no previous contact or relationship with participants and was new to the GaLEND evaluation team. The rationale for using a neutral, unfamiliar interviewer was to encourage more candid discussions about trainees' GaLEND experiences by reducing the effects of social desirability biases (Bergen & Labonté, 2020). The interviewer met with participants in a quiet, private office while using Webex to maintain participant confidentiality. After informed consent was obtained, audio-recording of the interview began. Interviews ranged from 14 minutes to 36 minutes ($M = 22$ minutes). All interviews were conducted between June 2021 and September 2021.

Webex recordings automatically generated written transcripts of the interviews, which were reviewed by the same research team member who conducted the interviews to address any errors or unclear sections of the recordings. Any identifying information was removed from each

transcript, and interviewees were assigned a pseudonym to ensure confidentiality. Once transcripts were checked and edited, they were sent to participants to confirm their perspectives were captured correctly and to ensure all identifying information was removed.

Analysis

Consensual Qualitative Research (CQR; Hill & Knox, 2021) methods were used in data collection and data analysis. These methods are guided by a constructivist, post-positivist theoretical framework in which meaning is derived from participants' reflections and the researchers' interpretations of these reflections. Data analysis was conducted through discussions with research team members, unassisted by any qualitative analysis software. Two members of the research team met and read all transcripts and discussed the broad domains that arose out of each transcript. The resulting broad domains were compared across transcripts to identify domains that summarized and captured the ideas from all transcripts. These resulting domains were sent to another member of the research team who served as the auditor. The auditor reviewed the proposed domains and flagged sections that might need discussion and revision. The two primary coders and the auditor convened to discuss the sections flagged by the auditor and arrive at a consensus about the final set of broad domains. From these discussions, it was apparent that some of the preliminary domains were related and these were collapsed into five final domains. After the broad domains were established, the same process was used to arrive at a consensus on specific core ideas for each domain.

Results

Self-advocate trainees were asked about their experiences in the GaLEND program and shared information about the importance of including self-advocacy as a discipline in LEND programs and the accommodations and supports that facilitated their inclusion in the program.

Following the CQR process of thematic coding, five domains emerged. These five thematic domains and the core ideas within each domain are presented in Table 2 and described in the narrative that follows.

INSERT TABLE 2 ABOUT HERE

Domain 1: Inclusion of Self-Advocate Trainees and Importance to the Program

Interviewees shared their thoughts on the value of including self-advocate trainees in LEND programs. The majority of interviewees explicitly stated they felt included throughout their training year in the GaLEND program. In addition, multiple interviewees provided concrete examples of the ways in which they were included in the program, including having their ideas valued in discussions and being able to participate in all training opportunities. Some interviewees also described being included in GaLEND beyond their training year in a variety of ways (e.g., being invited to speak to future cohorts). Overall, interviewees endorsed the value of LEND participation and its impact on their lives. For example, in describing his experience in GaLEND, Cameron said:

If anyone was interested in Georgia LEND, I would say, ‘Hey, you should totally do it because it's where everybody comes into a room to share ideas, and that's where everybody learned how to work together and learned how to be a leader.’

Interviewees also described factors that supported the inclusion of self-advocate trainees in the program. These factors included a program culture of inclusion, faculty who were invested in mentoring self-advocate trainees, individualized accommodation planning, and social connections with the cohort and faculty. Participants indicated that these factors promoted their feelings of inclusion and belonging in the GaLEND program. For example, Emma described how the program culture influenced her perceptions of inclusion: “When you walk in the room,

you feel good or belonging because you're in a professional environment [where] the faculty is there to remind you that as a self-advocate and family member, you are the expert in disability."

Importance of Self-Advocate Representation and the Value of Diverse Training Backgrounds

Interviewees shared their thoughts on the importance of including self-advocates in GaLEND and how their presence adds to the diversity of GaLEND trainees. Interviewees indicated that, in the GaLEND program, they were (a) viewed as experts in the "lived experience" of disability and (b) encouraged to share their expertise and experiences in class discussions. Interviewees indicated they believed self-advocate participation enriched the training for emerging professionals in disability-related fields by allowing them to (a) see greater possibilities for people with disabilities, (b) hear about real-life examples of inaccessibility and the need for continued advocacy to improve systems of care for people with disabilities, and (c) better understand their roles as future professionals and leaders in disability-serving organizations. Interviewees indicated that the inclusion of the "disabled voice" was integral to the LEND program and should be expanded in more training components. In describing how the inclusion of self-advocates shaped the GaLEND program, Jordan noted:

It adds that disabled voice to the table. And so, I think the Georgia LEND model is really unique because it gives you a glimpse of what it could be like if actual professionals and individuals with disabilities [are both] becoming professionals, and not like either/or. I feel like that "either/or" narrative, it kind of contradicts what you're trying to teach people in the first place, which is that people with disabilities should be included in everything.

Interviewees also described the personal benefits they experienced through participating. More than one interviewee described the value of interacting with professionals in a non-hierarchical, nonmedical setting. Another identified benefit was feeling empowered to learn in

academic contexts. They also described how the program fostered their personal development, including improving their self-advocacy skills and deepening their understanding of the larger disability community.

Interviewees also indicated that they were positively impacted by exposure to a diverse group of training backgrounds in GaLEND. Most indicated that the wide range of discipline representation in LEND resulted in richer discussion and dialogue. Further, interviewees indicated this diversity of disciplines helped them feel more comfortable interacting with diverse groups of people in professional settings. For example, Peter noted:

I also learned a lot about psychology, and I learned about physical therapy, and I learned about all these other things as well, so it really helped with my work within the legislature... making sure I could connect to everyone and not just people with disabilities.

Peter continued by discussing how the diversity of disciplines enabled a level of interdisciplinary dialogue that frequently does not occur in practice settings:

We all work together, but we're all separate. And people in the psychology world, don't talk to people in the physical therapy world, or the dental folks don't talk to the people that will be a doctor diagnosing people. And we're all connected and, the thing is, we need to make sure that we're all talking to each other.

Moreover, some interviewees felt the rich interdisciplinary discussions helped all GaLEND trainees gain a fuller perspective on the intersections (and sometimes disconnects) between the science about disability and the lived experience of individuals with a disability. Emma spoke to this, noting:

I think [GaLEND] gives the trainees a very holistic perspective because if you don't talk, if you don't have a discussion with a person with a disability, and there are no people with disabilities in the room, you're not ever going to get the full perspective.

Domain 2: Trainee Self-Identified Learning Styles and Instructional Preferences

Interviewees were asked to describe their self-identified learning preferences and unique learning needs, and whether the GaLEND curriculum adequately addressed their learning needs and preferences. Overall, interviewees endorsed that the GaLEND curriculum matched their preferred learning style. Self-advocate trainees generally described a wide range of self-identified learning styles, including auditory, visual, and kinesthetic (or “hands-on”) learning styles. Some interviewees indicated that multiple learning styles were appropriate for them, while others explained how some learning styles were not appropriate for them given their unique needs. For example, in discussing learning styles, Alex noted his preference for multimodal instruction:

“My learning style is best when I am able to see the content and hear it. (...) I don't like the whole structured classroom setting where it's strictly listening and taking notes because all my senses need to be tapped into.”

Many interviewees also identified preferred instructional modalities that address their learning needs. These included interaction and discussion-based learning, multimodal and multisensory learning approaches, explicit instruction, and repetition of course content and instructions. For example, Amelia discussed how her learning style was best met through explicit instructional approaches: “I don't get details and stuff. I need to be told what's in front of me, like, what the meaning of things are.”

These identified modalities differ from accommodations (discussed in a subsequent domain) in that they represent the approaches interviewees felt were useful for facilitating their learning and engagement across a variety of contexts, rather than identifying specific accommodations or instructional approaches that were implemented in the GaLEND program.

Domain 3: Accommodations and Supports

Interviewees were asked to describe accommodations that contributed to their inclusion and success in the program as well as the process by which accommodations were requested and received. While most interviewees reported using a variety of accommodations throughout their GaLEND training year, interviewees also identified social or interpersonal supports as integral to their success and inclusion in the program.

Accommodations

All but one interviewee described needing accommodations during their GaLEND training year. Some of these accommodations were formally requested and other supports were systematically embedded in the course. The one interviewee who did not report requesting or using accommodations subsequently identified and described the interpersonal supports they used during their GaLEND training year.

Most interviewees indicated they initiated accommodation requests in response to a barrier to learning, but two interviewees indicated that they initiated these requests at the start of their training year. Some interviewees indicated conversations about accommodation needs were ongoing and collaborative throughout the training year. Further, one trainee stated that accommodations were received, although they were not requested by the trainee. Two interviewees described a lack of “red tape” in getting accommodations through GaLEND compared to previous experiences requesting accommodations in other academic settings. For

example, Noah described how this lack of “red-tape” or formal processes in requesting accommodations helped facilitate more individualized supports:

When I was in college, they had a list of accommodations that would be sent to the professor formally, and all the red tape would be gone through as far as accommodations and all that. But we were still expected to talk to the professor individually and work through things. I like that from the outset (...) that the accommodations part, as far as putting things on paper, wasn't really a concern and the fact that individualizing the experience as much as we could within the constraints of what we had to do— I loved that that was the main focus.

Interviewees identified a wide range of personal learning needs, and they described a variety of accommodations implemented to address those needs. Accommodations described included large print, captioning on videos, use of microphones, availability of accessible online materials, videotaped class discussions, assistive technology (e.g., speech-to-text software), principles of Universal Designs for Learning (e.g., multiple means of action/expression), video conferencing, the ability to take breaks during class, pre-teaching and pre-viewing material, and having additional time to discuss content or get clarification about the material after class.

Many interviewees indicated that the accommodations met their learning needs and helped them succeed in the program. Some also explicitly stated how these supports supported their independence and full participation in all program activities. Furthermore, as Peter described, ongoing conversations about accommodation needs were important in promoting full participation as well: “Keeping that open line of communication really helped, and it really made sure that I was getting full participation within the LEND program.”

Interpersonal Supports

In addition to accommodations, interviewees also described social supports as integral to their success and inclusion in GaLEND. These interpersonal supports were described as coming from GaLEND faculty and fellow trainees.

Faculty were described as supporting interviewees by listening to accommodation needs, implementing accommodations, and helping to organize online material and course content. As described above, interactions with and support from faculty was described as an important source of support. Some interviewees indicated meeting with faculty to preview or review material covered in courses was essential to their success in the GaLEND program. Mariah described how meeting with faculty helped her engage in the required coursework: “Every Friday, we'd talk over what we did in class. [The faculty member] helped me understand it a lot better. And just processing it made me do my work a little bit harder as well.”

Emma also indicated GaLEND faculty not only promoted her success in the GaLEND program, but also mentored her to become a better self-advocate: “Beyond the classwork and accommodations, the staff still did a great job of mentoring me to be the self-advocate that I am today.”

In addition to support from faculty, interviewees also described how their cohort members often supported their learning needs and facilitated their success in the GaLEND program. For example, cohort members sometimes helped interviewees by providing transportation to off-campus activities. Interviewees also described how the connections with fellow trainees facilitated their learning through the opportunity to engage in deeper conversations about GaLEND course content and training experiences.

Domain 4: Workload and Program Expectations

Interviewees were asked to describe the workload and collaborative group assignments in GaLEND. Their responses generally reflected their success in managing program expectations for both individual and collaborative assignments.

Managing the Workload

Most interviewees indicated the program expectations and workload were demanding. In addition, they sometimes found the presented concepts difficult to understand. Most interviewees also noted it was especially difficult to manage the workload while balancing other personal and professional responsibilities. In some cases, difficulty accessing and navigating the online course webpage exacerbated these challenges. The balance between the high demands and the ability to manage the workload was highlighted by Cameron who stated: “It was a lot. Let me tell you that. It was, [but] it wasn't something that I couldn't handle.”

While the interviewees indicated that the workload was demanding, they also indicated that it was mostly manageable. They described several strategies they used to manage the workload including taking breaks, finding support to understand concepts and content, engaging in self-care, implementing time management strategies, working with peers, advocating for their needs, and just giving their best effort. Mariah highlighted many helpful strategies for managing the workload: “I am very organized and yes, [the GaLEND faculty] are extremely demanding with a lot of stuff. And because of my organization, I had to learn how to color coordinate my calendar.”

Collaborative Work in GaLEND

Interviewees’ perspectives on collaborative work in LEND varied considerably. Some indicated that the program’s collaborative nature contributed to their success in GaLEND, and

others described negative experiences in collaborative work. In addition, a handful of interviewees described both the positive and negative aspects of engaging in collaborative work.

Interviewees who described positive experiences engaging in collaborative work often indicated they felt empowered to take leadership on group assignments. They felt that their opinions and ideas were listened to and that their peers were generally very helpful and supportive. Some interviewees described strategies they used to promote more effective collaborative work. These strategies included creating a group schedule to ensure they had time to discuss projects with cohort members and dividing work equally among group members. In describing his positive experiences with collaborative work, Cameron highlighted the importance of dividing work tasks and valuing everyone's contributions:

It was really great. We worked together. We had different parts [of the project] that we looked at and if I needed help, they really helped me through the parts that I needed help with. Everyone worked together and everybody accepted each other's work experience, and how they work, and how they learn.

Interviewees who had less positive experiences with collaborative work described a number of difficulties in group assignments. Some individuals experienced conflict with group members over managing outside responsibilities. Others expressed how group members often had different opinions and experiences that made reaching an agreement challenging. Some interviewees noted that their groups did not engage in strategies to divide work appropriately among group members, which resulted in some individuals doing more work than others. One interviewee described how a lack of communication and leadership in the group created significant challenges, including the perception that some group members did not value everyone's input equally. Other factors that hindered collaborative work included inconsistent

meeting times, not enough faculty support in structuring group tasks, lack of background knowledge about the topic among group members, and cohort members who were not understanding of self-advocates' needs.

Peter (who described both positive and negative experiences with collaborative work) offered some suggestions for promoting future positive experiences in collaborative work in GaLEND:

It's really kind of hit or miss. Like, some of them can be really, really good because you have a really good, strong group, and then sometimes it's just kind of you get what you get type of thing (...) I think having a little bit more of faculty support would be fantastic on those events, I think.

Domain 5: Challenges with Participation and Suggestions for Improvement

Interviewees shared about the barriers that arose during their GaLEND training year. Some of these barriers were explicitly stated as having been resolved through accommodations or support. For example, interviewees described transportation as a barrier, especially to off-campus activities. Transportation issues were often addressed through carpooling with cohort members. Another barrier was being unable to hear classroom instruction and conversation, which was addressed through captioning and microphone use. Other barriers included difficulty using course technologies and learning platforms, material that was sometimes challenging to understand, and lengthy class sessions with not enough breaks. For example, Charlotte reflected on the need for more plain language to address barriers to understanding content when asked for suggestions for future improvement:

More plain language.... The word "discipline" isn't always plain language, I think. And I know that's words that MCHB uses, but I think that MCHB needs to understand if they

want to include people with disabilities as trainees, then they need to make sure it's accessible to everyone.

Interviewees also reflected on the drawbacks of participating in GaLEND. The most common identified drawback was difficulty with balancing program requirements with personal and professional responsibilities. In addition, some interviewees noted that remote learning options (implemented during the COVID-19 pandemic) were less effective and led to decreased opportunities to make connections and network with their cohort members. In addition, some interviewees felt there needed to be a better explanation of the larger purpose of LEND as well as the connection between the knowledge gained in LEND and applications in real-world settings. For example, Jordan shared her perspectives on needing a greater connection between the course content and real-world applications:

I'm kind of like a go-getter. But I can see for someone who maybe not have that ambition, or maybe is not as confident in that area, how you can feel like, "Okay, I just learned all this great information. How do I take this and apply it in the real world in real life experiences?"

To address some of the barriers and drawbacks to participation in GaLEND, interviewees offered some suggestions for program modifications and improvements. These included the use of more plain language, posting audio or video recordings of lectures, providing more breaks during class sessions, adjusting assignments to be more evenly spaced throughout the semester, encouraging equal collaboration between cohort members, providing clearer directions and expectations for assignments, having more opportunities to meet with faculty to discuss content and concerns, and engaging in more social activities outside of class to build cohort

relationships. Noah reflected on how having more social activities outside of class might facilitate greater learning in the GaLEND program:

I would love to see even more time outside of the classroom— more social activities, ways to connect, and things like that— because the more we were connected as time went on the easier it was to have discussions, and the more I got out of it, and I believe everybody else got more out of it as a result.

Discussion

The benefits of including self-advocacy as a formal discipline in LEND programs has been studied through the perspectives of traditional trainees from professional disciplines (Rosenberg et al., 2018). However, little research has examined how self-advocate trainees view the importance of their inclusion and the benefits of participating in interdisciplinary training programs. Findings from this study addressed why self-advocate representation is important in the LEND program and the benefits of including self-advocates. In addition, these interviews revealed important information about the kinds of accommodations and supports that can promote meaningful inclusion of self-advocate trainees. With these supports, self-advocate trainees were able to engage in all learning opportunities in the GaLEND program. Overall, the results highlight the importance of self-advocate representation for LEND programs and provide helpful insights into strategies for promoting future self-advocate success in LEND and other postsecondary educational programs.

Importance of Including Self-Advocates

Self-advocate interviewees endorsed a wide range of benefits of LEND participation, including enhanced communication skills, understanding of other professional disciplines, and an appreciation for interdisciplinary care. In addition, they were also motivated to seek employment

and educational opportunities in which they could continue to use and further develop these skills. In previous research, trainees from professional disciplines have endorsed similar benefits of LEND participation (Rosenberg et al., 2015). Thus, participation in LEND programs may benefit self-advocate trainees in similar ways as trainees from professional disciplines.

In addition, interviewees suggested they experienced improved self-advocacy and various interpersonal skills. Improved self-advocacy may benefit individuals with disabilities in a variety of contexts, including persistence in higher education (Kutscher & Tuckwiller, 2019), obtaining workplace and educational accommodations (Lindsay et al., 2018a, 2018b), and enhanced leadership skills in educational, workplace, and community contexts (Ryan & Griffiths, 2015). Thus, participation in LEND programs (and higher education more broadly) has the potential to promote positive outcomes for self-advocates across educational, occupational, and community contexts.

While the personal benefits to participation are notable, findings also suggest the inclusion of self-advocate trainees enriches the training experience of all trainees. Interviewees described how the GaLEND program valued their lived experiences and continually reminded all trainees of the expertise of self-advocates. This was seen as enabling *all* trainees to see the positive possibilities for people with disabilities and their roles and responsibilities in improving systems of care for people with disabilities. This finding corroborates previous research that found the inclusion of self-advocate trainees fosters a better appreciation for interdisciplinary teamwork and person-centered care in trainees from professional backgrounds (Rosenberg et al., 2018). Thus, the inclusion of self-advocate trainees may similarly promote skills and dispositions that improve professional trainees' capacity to engage in more inclusive practices across work and community settings.

Accommodation Access for Trainee Success

While interviewees indicated that the GaLEND curriculum was delivered in ways that met the needs of a diverse group of learners, barriers to learning still arose that required accommodations or interpersonal supports. Many of the barriers described were addressed through accommodations, which often were provided at the request of the self-advocate trainee. Initiating these conversations required a high degree of self-advocacy skills. Thus, it is important for LEND programs to consider how self-advocacy skills influence accommodation access.

Some interviewees indicated the process for requesting accommodations in GaLEND was especially effective due to the “lack of red-tape” or formal requirements. Because of this, they were able to bring up needs as they arose and seek support with greater ease. Previous research suggests that students with disabilities may prefer when the processes for requesting accommodations are met with this level of support (Kurth & Mellard, 2006). Indeed, resistance to accommodations by faculty and staff is often a significant barrier to the success of students with disabilities in higher education (Cawthon & Cole, 2010; Quinlan et al., 2012). Thus, it is imperative that postsecondary educational programs, like LEND programs, consider ways to promote faculty support for individuals with disabilities, such as providing faculty with specific training on effective implementation of accommodations (Garrison-Wade, 2012; Katsiyannis et al., 2009).

In addition to individualized accommodations, some trainees described benefiting from supports embedded systematically by faculty, suggesting postsecondary programs may create more accessible instructional contexts that deliver content via multiple modalities, provide multiple ways of engaging with content, and allow multiple ways of demonstrating knowledge (Rose et al., 2006). Indeed, structural supports to promote accessibility can promote access and

engagement for all trainees, not just self-advocate trainees with disabilities (Black et al., 2015; Capp, 2017).

Interpersonal Supports for Promoting Inclusion

While interviewees benefitted from receiving accommodations, many also described the importance of faculty and cohort members' support in meeting their learning needs. Interviewees indicated that GaLEND faculty were integral to their inclusion and success. Indeed, faculty support is associated with better educational outcomes and access to accommodations among individuals with disabilities across a variety of postsecondary educational settings (Kutscher & Tuckwiller, 2019; Quinlan et al., 2012).

Interviewees described how the personal connections with cohort members and faculty were essential to facilitating deeper conversations that enabled them to make more meaningful connections to the content. Thus, LEND programs should consider how to build social connections and meaningful discussions among cohort members. One way this may be facilitated is through facilitating intentional peer connections. For example, Graybill and colleagues (2020) described how a self-advocate trainee and a fellow GaLEND cohort member met consistently to discuss course content. However, the self-advocate trainee in Graybill et al. (2020) still indicated they sought additional peer support from other cohort members as well. Pairing self-advocate trainees with another LEND trainee provides peer support and helps build social connections and engagement, but programs should also consider how they can ensure self-advocate trainees connect with the whole training cohort as well.

Limitations

This study offers rich information about the experiences of 10 self-advocate trainees from the GaLEND program. While the sample size was appropriate for a qualitative investigation, it

may limit generalizability to other programs and contexts. Furthermore, the interviewees were former trainees from only one LEND program. Thus, the experiences represented in this study only reflect the experiences from a single program. In addition, the sample represented a wide variety of disabilities. Thus, specific strategies for including individuals with specific disabilities were not investigated for the purpose of this study.

Another potential limitation is that interviewees' reflections on past experiences in the GaLEND program may have been influenced by positivity bias or social desirability bias. As interviewees reflected about their past experiences, they may have focused on positive experiences in the GaLEND program, or they may have reported more positive experiences to convey their support of the program. This was addressed by utilizing a neutral interviewer with no previous relationship with participants and including interview questions that specifically sought input on the drawbacks to participating and suggestions for improvement (Bergen & Labonté, 2020). Self-advocate trainees in this study appeared to report both positive reflections about their experiences as well as possible areas in which improvement could be made. Thus, effects of the social desirability bias and positivity bias were hopefully minimized.

Future Directions

Given the study's limited sample size and focus on a specific training program, future research may seek to investigate the experiences of a greater number of self-advocate trainees from other LEND programs. Investigating the experiences of self-advocates from a variety of programs may provide information on a wider range of approaches to and strategies for including self-advocates. While previous work has investigated the benefit of including self-advocate trainees from the perspectives of trainees from professional disciplines in a different LEND program (Rosenberg et al., 2018), further examination of these benefits across multiple LEND

programs may facilitate a greater understanding of the role and impact of self-advocates across many LEND programs.

This study offered information about the importance of including self-advocates in interdisciplinary training programs and supports that can facilitate their success and full participation in training activities. A future study might continue to investigate the importance of self-advocate participation in LEND in other ways. For example, researchers could examine changes in self-advocate trainees' perceived leadership competencies or knowledge over the course of the LEND training. Self-advocates in this study indicated they gained confidence and skills in working with a diverse group of professionals, suggesting self-advocate trainees may experience growth in many of the MCHB Leadership Competencies (U.S. Department of Health and Human Services, 2018).

Conclusion

The results of our study suggest inclusion of self-advocate trainees is an important element of interdisciplinary training that can lead to richer and deeper understandings of disability among all trainees. Further, while accommodations were viewed as important for promoting access to content, self-advocate trainees indicated that interpersonal supports from faculty and peers were essential for their active engagement and full participation within the GaLEND program. Thus, it is critically important that postsecondary educational programs, especially LEND programs, consider the ways in which they may support individuals with disabilities through accommodations *and* interpersonal supports to ensure individuals are meaningfully included in educational settings and experience the benefits of participation in higher education.

References

- Abreu, M., Hillier, A., Frye, A., & Goldstein, J. (2016). Student experiences utilizing disability support services in a university setting. *College Student Journal*, 50(3), 323–328.
- Association of University Centers on Disability. (n.d.). *LEND Self-Advocacy Discipline Network*. Retrieved July 13, 2022, from <https://www.aucd.org/itac/template/page.cfm?id=1198>
- Bergen, N., & Labonté, R. (2020). “Everything is perfect, and we have no problems”: Detecting and limiting social desirability bias in qualitative research. *Qualitative Health Research*, 30(5), 783–792. <https://doi.org/10.1177/1049732319889354>
- Black, R. D., Weinberg, L. A., & Brodwin, M. G. (2015). Universal design for learning and instruction: Perspectives of students with disabilities in higher education. *Exceptionality Education International*, 25(2). <https://doi.org/10.5206/eei.v25i2.7723>
- Capp, M. J. (2017). The effectiveness of universal design for learning: A meta-analysis of literature between 2013 and 2016. *International Journal of Inclusive Education*, 21(8), 791–807. <https://doi.org/10.1080/13603116.2017.1325074>
- Cawthon, S. W., & Cole, E. V. (2010). Postsecondary students who have a learning disability: Student perspectives on accommodations access and obstacles. *Journal of Postsecondary Education and Disability*, 23(2), 112–128.
- Dunn, W., Brown, C., & McGuigan, A. (1994). The ecology of human performance: A framework for considering the effect of context. *American Journal of Occupational Therapy*, 48(7), 595–607. <https://doi.org/10.5014/ajot.48.7.595>
- Garrison-Wade, D. F. (2012). Listening to their voices: Factors that inhibit or enhance postsecondary outcomes for students with disabilities. *International Journal of Special Education*, 27(2), 113–125.

- Graybill, E., Esch, R. C., Vinoski, E., Truscott, S., Torres, A., Daniel, K., Crenshaw, M., & Crimmins, D. (2016). Including the family member in interdisciplinary team meetings: Communication trend analysis. *Small Group Research*, 47(1), 3–27.
<https://doi.org/10.1177/1046496415604028>
- Graybill, E., Thomas, E. V., Baker, K., Truscott, S., Crenshaw, M., Heggs Lee, A., & Crimmins, D. (2020). Supporting the participation of individuals with disabilities in a graduate-level leadership training program: Lessons learned through a case study approach. *International Journal of Disability, Development and Education*, 1–10.
<https://doi.org/10.1080/1034912X.2020.1812540>
- Hill, C. E., & Knox, S. (2021). *Essentials of consensual qualitative research*. American Psychological Association. <https://doi.org/10.1037/0000215-000>
- Katsiyannis, A., Dalun Zhang, Landmark, L., & Reber, A. (2009). Postsecondary education for individuals with disabilities: Legal and practice considerations. *Journal of Disability Policy Studies*, 20(1), 35–45. <https://doi.org/10.1177/1044207308324896>
- Keisling, B. L., Bishop, E. A., & Roth, J. M. (2017). Integrating family as a discipline by providing parent led curricula: Impact on LEND trainees' leadership competency. *Maternal and Child Health Journal*, 21(5), 1185–1193. <https://doi.org/10.1007/s10995-016-2217-4>
- Kurth, N., & Mellard, D. (2006). Student perceptions of the accommodation process in postsecondary education. *Journal of Postsecondary Education and Disability*, 19(1), 71–84.

- Kutscher, E. L., & Tuckwiller, E. D. (2019). Persistence in higher education for students with disabilities: A mixed systematic review. *Journal of Diversity in Higher Education*, 12(2), 136–155. <https://doi.org/10.1037/dhe0000088>
- Lindsay, S., Cagliostro, E., & Carafa, G. (2018a). A systematic review of barriers and facilitators of disability disclosure and accommodations for youth in post-secondary education. *International Journal of Disability, Development and Education*, 65(5), 526–556. <https://doi.org/10.1080/1034912X.2018.1430352>
- Lindsay, S., Cagliostro, E., & Carafa, G. (2018b). A systematic review of workplace disclosure and accommodation requests among youth and young adults with disabilities. *Disability and Rehabilitation*, 40(25), 2971–2986. <https://doi.org/10.1080/09638288.2017.1363824>
- Madaus, J. W., Kowitt, J. S., & Lalor, A. R. (2012). The higher education opportunity act: Impact on students with disabilities. *Rehabilitation Research, Policy, and Education*, 26(1), 33–41.
- Quinlan, M. M., Bates, B. R., & Angell, M. E. (2012). ‘What can I do to help?’: Postsecondary students with learning disabilities’ perceptions of instructors’ classroom accommodations. *Journal of Research in Special Educational Needs*, 12(4), 224–233. <https://doi.org/10.1111/j.1471-3802.2011.01225.x>
- Rose, D. H., Harbour, W. S., Johnston, C. S., Daley, S. G., & Abarbanell, L. (2006). Universal design for learning in postsecondary education: Reflections on principles and their application. *Journal of Postsecondary Education and Disability*, 19(2), 135–151.
- Rosenberg, A., Margolis, L. H., Umble, K., & Chewning, L. (2015). Fostering intentional interdisciplinary leadership in developmental disabilities: The North Carolina LEND

experience. *Maternal and Child Health Journal*, 19(2), 290–299.

<https://doi.org/10.1007/s10995-014-1618-5>

Rosenberg, A., Zuver, D., Kermon, M., Fernandez, C., & Margolis, L. H. (2018). Reflections on the contributions of self-advocates to an interdisciplinary leadership development program for graduate students in health affairs. *Disability and Health Journal*, 11(2), 293–297. <https://doi.org/10.1016/j.dhjo.2017.09.002>

Ryan, T. G., & Griffiths, S. (2015). Self-advocacy and its impacts for adults with developmental disabilities. *Australian Journal of Adult Learning*, 55(1), 31–53.

Summers, J. A., White, G. W., Zhang, E., & Gordon, J. M. (2014). Providing support to postsecondary students with disabilities to request accommodations: A framework for intervention. *Journal of Postsecondary Education and Disability*, 27(3), 245–260.

U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. (2018). *Maternal and Child Health Leadership Competencies*. Rockville, Maryland: U.S. Department of Health and Human Services.

Vargas, C. M., Arauza, C., Folsom, K., Luna, M. del R., Gutiérrez, L., Frerking, P. O., Shelton, K., Foreman, C., Waffle, D., Reynolds, R., & Cooper, P. J. (2012). A community engagement process for families with children with disabilities: Lessons in leadership and policy. *Maternal and Child Health Journal*, 16(1), 21–30.
<https://doi.org/10.1007/s10995-010-0666-8>

Figure 1*Semi-Structured Interview Protocol*

1. What was your discipline in GaLEND?
2. During what year(s) were you a LEND trainee?
3. GaLEND can be demanding- in terms of time as well as the level of material you are presented during class. Tell me about your learning style.
Prompts:
 - Was the way the GaLEND curriculum presented appropriate for your learning style?
 - What techniques did/do you use outside of class to learn the material and manage your time in the program?
 - Was the course workload manageable? What strategies did you use to help get the work done?
4. Did you request or receive any accommodations related to the GaLEND curriculum and out-of-class activities during your training year?
 - If yes, please describe the accommodations and continue
 - If no, move to item 5**Prompts:**
 - Were these accommodations given by your request or did the GaLEND faculty and team make these accommodations for you without your input?
 - When was the first time you discussed these accommodations with the team?
 - What worked with your accommodations experience in GaLEND? What could have been better?
5. Tell me about how GaLEND includes trainees from non-traditional backgrounds, such as self-advocates and family members.
Prompts:
 - How did/does this diversity impact your experience in GaLEND?
 - As a non-traditional trainee, what were some of the benefits and drawbacks of participating?
6. GaLEND is one of the only LEND programs in the nation that includes non-traditional trainees, such as self-advocates, family members, and trainees from non-MCH disciplines. How do you think the diversity of disciplines of GaLEND trainees helps shape the program?
Prompts:
 - GaLEND involves a lot of collaborative work between trainees from different disciplines. How was your experience in these collaborative assignments?
7. What could have been done differently to ensure your success/inclusion in GaLEND?

Table 1
Participant Information

Pseudonym	Disability
Emma	Cerebral Palsy
Jordan	Deaf/Hard of Hearing
Charlotte	Intellectual/Developmental Disability
Mariah	Sickle Cell Disease
Alex	Orthopedic Impairment
Amelia	Autism
Peter	Cerebral Palsy
Cameron	Intellectual/Developmental Disability
Noah	Cerebral Palsy
Madalyn	Down Syndrome

Table 2*Themes and Core Ideas from Responses*

Domains & Core Ideas	Frequency
1. Inclusion of Self-Advocate Trainees	
a. Inclusion of non-traditional trainees	General (9)
Trainees felt included	Typical (8)
Factors that supported inclusion	Typical (7)
Ways trainee described being included	Typical (6)
Benefits to participating	Typical (8)
b. Value of diverse training backgrounds	General (10)
Trainee valued diversity of training	General (10)
Richer conversations	Typical (7)
Contributes to a more holistic perspective for all trainees	Typical (6)
Gain comfort interacting with diverse groups of people	Variant (3)
c. Importance of Self-advocate representation	Typical (6)
Self-advocates are valued as experts in disability lived experience	Variant (4)
Enriches training for professionals	Typical (5)
Includes the disabled voice	Variant (3)
2. Trainee Self-Identified Learning and Instructional Preferences	
a. LEND curriculum matched learning needs	General (9)
b. Trainee's self-identified learning styles	General (9)
Auditory	Typical (5)
Visual	Typical (7)
Kinesthetic/ Hands-on	Variant (2)
c. Instructional modalities identified as helpful to trainees	Typical (6)
Interaction/ Discussion-based	Variant (2)
Multisensory/Multimodal instruction	Variant (1)
Explicit instruction	Variant (2)
Repetition	Variant (2)
3. Accommodations and Supports	
a. Accommodations	General (10)
Types of accommodations	General (9)
Accommodation helpfulness	Typical (7)
Accommodation process	General (10)
b. Interpersonal supports	General (9)
Faculty support	Typical (7)
Cohort support	Typical (7)
4. Workload and Program Expectations	
a. Managing the Workload	General (10)
Workload and program expectations were demanding	Typical (8)
Strategies that helped make workload manageable	Typical (7)
Trainee was able to manage the workload	Typical (8)
b. Collaborative Work	General (9)
Positive experiences in collaborative work and factors that facilitated collaborative work	Typical (6)
Negative experiences in collaborative work and Factors that hindered collaborative work	Typical (6)
5. Challenges with Participation and Suggestions for Improvements	
a. Types of barriers to participation	General (9)
b. Barriers were addressed through accommodations or resolved	Variant (4)
c. Drawbacks to participation	General (8)
d. Suggestions for improvement & meeting learning needs	General (7)



Click here to access/download
Supplemental Material
Acknowledgements.docx

