

A Case for Disability Leadership in Southwest Pennsylvania

James R. Davis, Jennifer R. Lundy, Kelly M. Hurst



Statement on Person First Language

As a research team, we acknowledge that language is an evolving medium. In the late 20th century, person-first language was adopted to acknowledge one's personhood and decenter identities that are historically marginalized. In current time, we find a desire by many within the disability community to reclaim one's disability identity as a central feature of how they interact with the world. These individuals embrace identity-first language.

Throughout our report, in recognition of these two equally valid perspectives, we may vary our use of person- or identity-first language with no intent to diminish our deeply held belief in the value of all life.

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James Davis

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In fulfillment of a promise (gratitude to Carl Sagan): *in the vastness of space and immensity of time, it was my profound joy to spend a planet and an epoch with **Morgan Wickham**.*

This profound work is done in the name of my aunts, **Dee Dee** and **Audrey**.

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My family: **Russell**: who kept me healthily fed, properly hydrated, and who shoved me into sunlight occasionally. **Mallory**, who has always been in school with me. **Mason**, who believed I could do it without hesitation. **Caitlin**, whose awe motivated me. My extraordinary sisters: **Erin**, and **Tracy** for unreserved tenderness. My distractingly cute grandchildren who were no help at all when I needed to study. We can play more now.

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Executive Summary

Organizational Overview

FISA Foundation is a charitable grantmaking foundation that funds and partners with nonprofits across southwestern Pennsylvania (SWPA). Their mission is to champion equity, justice, safety and inclusion for women, girls, and people with disabilities, combatting systemic racism that impedes progress for these populations in southwestern Pennsylvania. This profoundly important work aims to support vital communities where respect and dignity are paramount and where access to opportunity offers inclusivity for all. Their work evolves as they live into their commitments of centering the most harmed individuals.

Problem of Practice

In 2020, FISA began reckoning with intersectional discrimination and how it impacts the people whom they serve through their mission. An Advisory Committee on RACE + Disability was convened to gather perspectives and FISA discovered a need to develop more leaders in the disability community to lighten the burden on the small cadre of high-profile individuals who have been overtasked with advocacy and representation in the region.

With this need in mind, FISA connected with Chicago-based Disability Lead for a potential partnership. Disability Lead is a network of fellows from the disability community representing myriad identities who serve as change agents and positive disruptors. Their mission is to increase civic engagement and diverse leadership in the Chicago region by developing and building a network of leaders with disabilities – consistent with the spirit of the Americans with Disabilities Act. They were exploring an expansion of their leadership development program (LDP) model to share and expand to new metropolitan areas.

For this project, we explored features of the Disability Lead LDP in order to assess its adaptability to enhance skillsets and build robust professional and personal networks in the greater SWPA region.

The purpose of this study is to evaluate increased community advocacy and support for disabled persons via Disability Lead’s program for implementation in the Greater Pittsburgh market.

The project team engaged with FISA and Disability Lead, gained a greater understanding of the desires for the LDP expansion, and developed our project questions.

Project Questions

1. In what ways might FISA Foundation encourage more robust participation in their work from persons with disabilities in the SWPA region?
 - a. What are current barriers to participation?
 - b. What are current enablers to participation?
2. What adaptations, if any, are necessary to the Disability Lead model to serve the SWPA disability community?
3. How might FISA Foundation establish and maintain support for a new disability-focused leadership development program in SWPA?

Project Design

Data Collection

Both FISA Foundation and Disability Lead submitted files to the Capstone team for inclusion in the project. FISA provided video recordings of stakeholder meetings, meeting notes and focus group data. FISA Foundation documents contain stakeholder responses that directly address the first and third project questions.

Disability Lead documents included program assessment, needs assessment, and expansion plans as well as notes from meetings with various Disability Lead stakeholders. Importantly, their primary source data came from their program curriculum.

Our research produced 4 findings that focused on FISA's role in their region and 5 recommendations that could make possible successful implementation of adapting Disability Lead's leadership program.

Findings and Recommendations

Finding 1: FISA Foundation is a recognized, respected, and trusted advocate for the disability community in SWPA.

Finding 2: The region is home to myriad disability advocacy groups with little to no coordination between organizations.

Finding 3: Accessibility and financial support cannot be overemphasized.

Finding 4: Opportunities for mentorship are minimal due to the lack of leaders in the community who have a disability identity.

Photo courtesy of [fisafoundation.org](https://www.fisafoundation.org)



Based on our findings, we view opportunities in these recommendations that will merely enhance the work of FISA and fulfill the leadership development outcomes from their RACE + Disability committee.

Recommendation 1: FISA Foundation should leverage its trusted reputation as convener for disability rights to mobilize institutional and political supporters.

Recommendation 2: FISA should secure commitments and support from key institutional partners.

Recommendation 3: FISA should identify strong mentors from the greater SWPA region and cultivate compelling examples of success while leading with one's disability.

Recommendation 4: FISA should include accommodations as a base expectation in program components.

Recommendation 5: FISA should ensure all financial barriers to participation are addressed including lost wages.

I. Organization Context

FISA Foundation was founded in 1996 and is a charitable grantmaking foundation funding and partnering with nonprofits across southwestern Pennsylvania (SWPA). FISA looks for changemakers working to advance equity and justice for women, girls, and people with disabilities. In addition to grantmaking, FISA extends its capacity by convening grantees and partners, hosting education opportunities, and advocating with and for women, girls, and people with disabilities to fulfill their mission. The foundation, stewarding between \$40 and \$50 million in assets, is headquartered in Pittsburgh, Pennsylvania, and is governed by a 19-person Board of Directors. A staff of four (4) employees and numerous community volunteers manage the day-to-day operations.

In 2020, FISA Foundation began reckoning with intersectional discrimination. Concerns over racialized ableism elevated FISA's focus on racial justice and the specific experiences of persons of color with disabilities. An excerpt from a letter to grantees reveals the depth of this commitment and the self-reflection that brought FISA to this moment:



FISA Foundation champions equity, justice, safety, and inclusion for women, girls, and people with disabilities, combating systemic racism that impedes progress for these populations in southwestern Pennsylvania.



Photo courtesy of fisafoundation.org

It is a painful fact that every single system has embedded racism and that good intentions are not remotely sufficient to dismantle the ways discrimination plays out daily. Our silence has caused pain and suffering and has disadvantaged Black people and other people of color who live with disabilities or who are family members or service providers. This moment calls us to step forward, be honest, have vulnerable conversations about systemic racism, and then commit to driving real change.

(FISA Foundation, n.d.)

FISA followed up this statement by convening an Advisory Committee on RACE + Disability to gather perspectives and determine future actions. One resounding message from the Advisory Committee was the need to develop more leaders in the disability community as, currently, a small cadre of high-profile individuals serve many roles to represent the community in the region, overtasking them significantly. Current leaders state they are burning out and concerned about who will come after them or seize an opportunity when they are unavailable to participate.

II. Problem of Practice

With the need for a pipeline of new leaders in mind, FISA connected with Chicago-based Disability Lead for a potential partnership. Disability Lead is a network of members and fellows from the disability community representing different identities who serve as change agents and positive disrupters. Born out of the Chicago Community Trust (CCT) as a commemoration of the 25th Anniversary of the Americans with Disabilities Act (ADA), Disability Lead was looking to take their leadership development program (LDP) model and share it, expanding into new metropolitan areas. The Disability Lead model resonated with FISA leadership, who presented it to the RACE + Disability Advisory Committee, who enthusiastically responded. FISA has now committed to spending a year evaluating the program and how to implement it in the Greater Pittsburgh market potentially.

The logo for Disability Lead features the word "Disability" in a dark blue, sans-serif font, followed by a red plus sign, and the word "Lead" in a bold, orange, sans-serif font below it.

Disability Lead is a network of people with disabilities who use our power to create an equitable and inclusive society.

Currently, in SWPA, there are a small number of highly successful and well-renowned leadership development organizations, but none that focus on the disability community. Individual disability organizations have disability-specific programs, such as programs for young people with autism spectrum disorder or visual impairment. However, none currently seek to serve the broader intersectional disability community. Finally, much of the extant programming for leadership centers on youth and promotes self-advocacy leaving an open need for community advocacy that drives systemic and legislative changes.

As the advocates who drove major wins such as the Americans with Disabilities Act retire from their roles, it is increasingly important that new voices emerge to engage with politicians, businesses, and educational institutions to ensure full participation by members of the disability community in the spaces where decisions are made and systems are forged. Furthermore, it continues to be essential to demonstrate the value that

members of the disability community bring to the workforce. Programs that enhance skillsets and build robust professional and personal networks begin to advance equitable participation by members of the disability community in the workforce in an open way, free from the need to cover up their disabilities.

While a lack of dedicated programming seems to contribute to the shortage of emerging leaders, other likely factors are at play. Individuals may be uncomfortable identifying as disabled and avoid speaking openly about their identity for fear of adverse consequences. Other community members may be disinclined to identify as a leader, given the stigmatization society has placed on their particular disability. Others may more strongly align with race, gender, or sexual orientation as the predominant identity they choose to advocate for. FISA is actively engaged in listening sessions currently to address the perspectives of the disability community on such matters.

Evidence

Initial evidence of the problem surfaced during the RACE + Disability Advisory Committee from a diverse group of individuals. However, FISA has experienced the symptoms of this issue in its convening work, recruiting board members, and seeking disability advocates within critical organizations across the region. Key FISA board members and other partners affirmed the concern raised by the Advisory Committee. Since these initial conversations, FISA has continued to engage with representatives of the disability community to gather more information and to vet the Disability Lead model as an alternative for the region.

Emerging from these conversations is a sense that many factors contribute to the lack of new emerging leaders that must be considered and overcome. One such factor is whether members of the disability community sense that they are a candidate for a leadership program.

Assumptions and Biases

One underlying assumption that has shaped this area of inquiry is that FISA is an appropriate organization to tackle this issue for the SWPA region. Throughout FISA's year of evaluation, the FISA staff and board need to remain open to the prospect that another organization will be suitable to bring a new program into existence or that the community in SWPA does not support such a program.

The other fundamental assumption is that the community would want and avail themselves of a program. Again, the FISA team must remain open-minded and regularly evaluate the community's interests. All members of the organization and the capstone team were prepared to combat various-isms that may surface in considering solutions for a community, not least of which is ableism.



Photo courtesy of RDNE Stock project

FISA has continued to engage with representatives of the disability community to gather more information and to vet the Disability Lead model as an alternative for the region.

Parties of Interest

The central stakeholder in this project is the disability community in the SWPA area. Their interests should supersede all others due to the continued marginalization of this group. FISA and Disability Lead are directly relevant as the convener and partner. Many other regional players are also interested in this evaluation's success and potential program, including extant leadership development programs. Government entities, human services organizations, and other businesses have their own unique interests. Government entities like the city have panels and committees that would benefit from increased representation by the disability community. Human service organizations, particularly those directly

serving the disability community, have a vested interest in members of their beneficiary demographic having improved opportunities.

FISA and Disability Lead will use the information gathered over this year of evaluation to decide whether a program is appropriate and what parties should be involved in bringing it to life. Over this year, we expect that FISA and Disability Lead will solicit additional financial support from larger foundations and corporations. Finally, we expect the work over this year to greatly inform decisions about the features and design of a program - including portions adapted from Disability Lead.



Photo courtesy of Polina Zimmerman

III. Review of Literature

Extant literature bolsters the case for enhanced disability leadership in SWPA, which often misses the mark in identifying salient components of disability justice. To help provide context and guide our work on this project, we began with an exhaustive literature review on leadership and disability. A review of the collective literature identified three themes/framings regarding disability leadership. First, disability is a barrier to leadership; second, society commonly frames disabled persons as the beneficiaries of leadership rather than leaders; and third, self-advocacy is the primary opportunity for leadership by disabled persons. Below, we unpack the themes and describe how the literature amplifies the need for FISA Foundation's work. We also share how disabled individuals exist in a tug-of-war between the medical and social models of disability when considered for leadership opportunities.

Disability as a Barrier to Leadership

There are established and long-standing patterns of discrimination toward individuals with disabilities that have social and financial consequences (Holliman et al., 2023). Auchenbach (2020) highlights that while the COVID-19 pandemic negatively impacted persons with disabilities disproportionately, systemic racism exacerbated negative impacts, particularly financially. A National Disability Institute analysis of data published by the U.S. Census Bureau indicates that, generally, disabled people are more likely to live below the poverty line, have less education, and have lower savings and net worth than non-disabled persons, all of which contribute to one's employment opportunity (Auchenbach, 2020). Within the disabled population, Black, Indigenous, and Latinx people underperform in all categories.

Research into barriers to full participation helps clarify the current status quo, which adversely affects the disability community. Specific barriers to full participation addressed in the literature vary but include themes of preparation, funding, lack of support, and the need to 'cover' one's disability identity in specific settings (Caldwell et al., 2009; Emira et al., 2019; Landmark et al., 2017; Orkin, 2022; Shanouda et al., 2020). Just as the financial impacts described above, these barriers, too, become more prevalent when compounded with issues of race and gender (Auchenbach, 2020; Holliman et al., 2023).

Our research finds that the definition and perception of leadership by persons with disabilities are varied. We could not identify any research that spoke to the cultivation and development of disabled leaders. As such, we found no common language or universal understanding of effective leadership beyond self- or disability-focused advocacy roles.

Silence from researchers on persons with disabilities in leadership roles contributes to ambiguity but may further perpetuate social and systemic barriers in desperate need of dismantling.

In one study on leadership emergence and effectiveness, researchers define leadership emergence as the demonstration of leadership skills by individuals in informal situations and leadership effectiveness as the evaluation of persons in a recognized or formal leadership position.

The study suggests that informal opportunities often lead to formal leadership roles. However, disabled persons are less likely to emerge in informal settings without systemic organizational interventions (Luria et al., 2014). Interestingly, the same study also found there is no difference in effectiveness between non-disabled and disabled leaders as measured by peer evaluations and coursework, suggesting that lack of opportunity, not a person's disability, is the actual barrier.

Another barrier stems from the general perception of leadership and the perceived workload expectations that accompany leadership. This perception is also varied. While some view leadership as a formal, progressive process that brings status and authority, others associate leadership with significantly increased workloads. In the latter view, ableist stereotypes feature in preventing disabled people from consideration (Emira et al., 2018). Similarly, many people believe learning is central to leadership. Aspiring and current leaders value intellectual stimulation opportunities through classroom education and lived experiences. For persons with disabilities, they may not realize these opportunities due to a lack of supportive structures and societal stereotypes (Luria et al., 2014).

Building from the barrier of perception, concepts of well-being perpetuate ableist stereotypes in the workplace that interfere with goals of inclusion and belonging. For example, Luu (2019) suggests that benevolence and inclusivity are salient qualities cultivated in leaders to create "work-related well-being." He offers three dimensions of well-being: physical, psychological, and social. In concert, these are crucial for disability inclusion in the workplace but, when reflected on leadership, may put members of the disability community at a disadvantage. Each of these dimensions is further complicated when intersectional

identities combine with disability. Given that disabilities may be physical, intellectual, emotional, and social, a focus on well-being in these areas sets up a paradigm where persons with disabilities are, therefore, categorized as unwell. The ableist framing of Luu's dimensions cast non-disabled leaders as those taking care of disabled individuals and their well-being.

The barriers addressed thus far have focused on the expectations of others; barriers to leadership for disabled persons are categorized both as institutional (beyond the control of the individual) and personal (within the control of the individual) (Areheart, 2008; Emira et al., 2018). While institutional barriers are more prevalent in workplaces, data indicate that the two are intertwined. Areheart (2008) and Emira et al. (2018) suggest that working conditions, staff attitudes, and reactive support are three primary examples of institutional barriers. For example, staff attitudes towards disability contribute to a lack of disability disclosure, which in turn can reduce the availability of necessary support for individuals with disabilities to advance in leadership roles successfully. The lack of visible leadership by persons with disclosed disabilities throughout society is a significant deterrent towards leadership. This visibility is often impacted by staff attitudes and societal stereotypes about disabled persons, seeing them as dependent and unable to make sound decisions about their needs. Organizations often fail to take proactive measures to support full participation by persons with disabilities. Without proactive measures, line managers are left responsible for making reactive adjustments to support persons with disabilities (Areheart, 2008). As managers may lack sufficient training to meaningfully support emerging leaders with disabilities, the organizational and systemic structures do not contribute to the advancement of persons with disabilities.

Finally, barriers may come from the persons with disabilities themselves. Low aspiration to leadership and reluctance are two key personal barriers facing disabled employees. Low aspiration can be born out of an organizational culture where ableist beliefs among employees and leaders are present, training and skills opportunities are lacking, and staff attitudes demonstrate a reluctance to work with disabled persons. Awareness among disabled people of the non-supportive environment contributes to the second barrier, reluctance. Such attitudes may prevent disclosure of one's disability out of fear of discrimination. The absence of psychological safety likely impacts trust among colleagues in these environments (Areheart, 2008; Emira et al., 2018; Powers et al., 2002).

Disabled Persons not Framed as Leaders

Another way the literature addresses disability and leadership is by examining the inclusion of disabled persons. Discussed in this body of literature are topics such as managerial guidance (Luu, 2019), capacity building (Griffen, 2022), and organizational support needed for the participation of disabled persons (Caldwell et al., 2009; Smits, 2004; Wilson et al., 2013). Like the challenge outlined in the previous section, there exists a need for more agreement on a standard definition of inclusion. Such a gap often contributes to what Wilson and colleagues dubbed a "research versus practice hiatus," where the lack of established models prevents the development of best practices (Wilson et al., 2013, p. 344).

Stemming from the absence of explicitly established models for including persons with disabilities in leadership roles, the research examined failed to reveal any discussion framing disabled people as leaders or emerging leaders. Society readily positions non-disabled persons in informal and formal

leadership roles, suggesting that learning how to perform benevolent or altruistic leadership will help them be the best possible leaders and contribute to the well-being of disabled persons in the workplace. In contrast, persons with disabilities are often framed as recipients of needed leadership instead of being presented as exercising leadership (Emira et al., 2018; Griffin, 2022; Luu, 2019; Wilson et al., 2013).

Persons with disabilities are often framed as recipients of needed leadership instead of being presented as exercising leadership.

The research discusses mentorship as a means of achieving the inclusion of disabled people. In several ways, informal opportunities and mentorship rather than a systematic and comprehensive approach foster the development of leaders in the disability community (Emira et al., 2018; Luria et al., 2014; Orkin, 2022). Members of the disability community may also be called upon more often to serve in informal leadership roles in volunteer capacities, depriving them of more formal and compensated avenues (Emira et al., 2018), further widening financial disparities and devaluing the work of people with disabilities.

In this same vein, Wilson et al. (2013) devote a significant portion of the research to how mentorship through paid support, unpaid support, and community/faith-based support contribute to greater social inclusion. Their findings indicate that unpaid mentorship is an effective means to achieve the inclusion of disabled persons. However, this research struggles to position abled persons as the primary beneficiaries of mentorship arrangements and confines people with disabilities to limited expectations for advancement. Further, the authors acknowledge that workplace mentorship tends only to increase social inclusion and does not extend to external interactions. They do not explore increased opportunities for contribution or pathways to leadership for the mentored recipients. **Our search returned no articles on disabled individuals mentoring or leading abled individuals.**

The literature proposes limited solutions to increase the framing of persons with disabilities as leaders. Continued representation is needed to protect the gains made in the disability justice space and to advance beyond representation to full participation (Shanouda et al., 2020). Visible leadership by members of the disability community shows others that it is possible (Boscardin & Shepherd, 2020; Luria et al., 2014; Shanouda et al., 2020; Smits, 2004), and individuals living with disabilities regularly report the need for more mentors leading with greater authenticity to overcome ableism (Orkin, 2022). As suggested in the work on barriers to participation, proactive strategies offer a more promising result than reactive responses to problems as they arise.

Self-Advocacy Leadership

There are multiple works in the literature on leadership through self-advocacy. Scholars generally agree on the need to develop leadership capabilities for members of the disability community for the primary purpose of self-advocacy. Extensive research encourages self-advocacy to manage one's needs (Auchenbach, 2020; Griffen, 2022; Landmark et al., 2017; Smits, 2004).



There is far less research discussing leadership development. However, the self-advocacy research only scratches the surface of the role leaders from the disability community play in advancing universal prosperity and making advances that ultimately benefit many, even among those without a disability (Auchenbach, 2020; Griffen, 2022; Landmark et al., 2017; Smits, 2004). Blackwell articulates that, as we address barriers to participation for one group, they often support the needs of many other individuals, regardless of their ability, making society work better for all people (2016). Ultimately, viewing individuals with disabilities as capable of leadership rather than limiting their role to self-advocacy unlocks more significant potential for society.

More Data Needed for Disability-Focused Leadership Programming

The lack of literature on the experience and assessment of disabled leaders leads us to contend that such a gap reflects an opportunity for programming directed at leadership development. Caldwell (2010) suggests that opportunities for disabled persons to develop their leadership skills are in self-advocacy roles. In our search, no examples of research into leadership development by and for persons with disabilities were in the extant literature. Even Google searches for “disability leadership program” show results that each reference self-advocacy or supporting their communities. Such imbalance indicates the limited expectations set for individuals with disabilities.



Considering the case for leadership development specific to the disability community, the literature supports the argument that additional formal opportunities are needed. Additionally, several researchers have begun to explore the support necessary for members of the disability community to participate more fully in committee membership, advocacy, employment, and other aspects of leadership. Caldwell et al. (2009) sum it up by stating that support must be individualized and address the common barriers experienced by members of the disability community.

Impacting Structural Barriers

Several researchers have begun to explore the support necessary for members of the disability community to participate more fully in committee membership, advocacy, employment, and other aspects of leadership (Caldwell et al., 2009; Caldwell, 2010; Griffen, 2022). Though the literature does not address stand-alone disability-focused leadership development programs, the case for mentorship, training, and access to opportunities suggests that such programs have a role in advancing persons with disabilities into leadership roles. As FISA explores the next steps with Disability Lead, the case for formal structured programs and supports appears well supported and urgent.

Policies represent an elaborate formal structure used either to advance or to repress persons with disabilities. The literature also addresses policies used to provide leadership to disabled persons. Smits (2004) identifies two sources of challenges to inclusion via policy-based avenues. First, the constant evolution of our environment through regular advances in technology impacts employment infrastructures. Second is the ongoing transformational change of work, where individuals must constantly evolve their skills to maintain employment or competitiveness in many sectors (Smits, 2004). These challenges represent significant obstacles for policymakers and service providers who play a major role in developing support structures. When change happens rapidly, several factors may be necessary to support the interests of the disability community. Access to leadership roles and representation at the table where policy change happens is critical. We explore these matters more thoroughly as we craft a new model for leadership by persons with disabilities.

IV. Conceptual Framework and Project Questions

Separately from the barriers, framing, and emphasis on self-advocacy present in the literature, over the last 75 years, the model for disability underwent a dramatic shift. Parsons, in the medical model of disability, posited disability from a deficit perspective, a tragedy to be remedied (1951). The natural consequences of such a model result in persons with disabilities positioned as less than full humans, flawed, and in need of assistance. New models, such as the social model, advance an understanding of society's role in placing barriers to accessibility in the path of individuals with disabilities (Zajadacz, 2015). The importance of this shift cannot be overemphasized in its placement of society in the driver's seat to remedy these barriers rather than the individuals with disabilities' responsibility to overcome them.

A social model of disability recommends the removal of barriers, which frequently result in changes that support many populations beyond those with the disability addressed. A seminal example of such a change is the curb-cut effect, whereby cutting wheelchair access into curbs on streets and intersections made sidewalks more navigable for wheeled carts, strollers, and joggers alike (Blackwell, 2017). By extension, one can anticipate removing barriers to leadership for persons with disabilities to provide opportunities for other historically disadvantaged populations.

From the basis of the social model, we then turn to the literature on leadership development models. The Social Change Model of Leadership Development establishes three levels at which leadership operates: individual, group, and community or societal (Higher Education Research Institute, University of California, 1996). This model acknowledges the interdependence of the levels and the

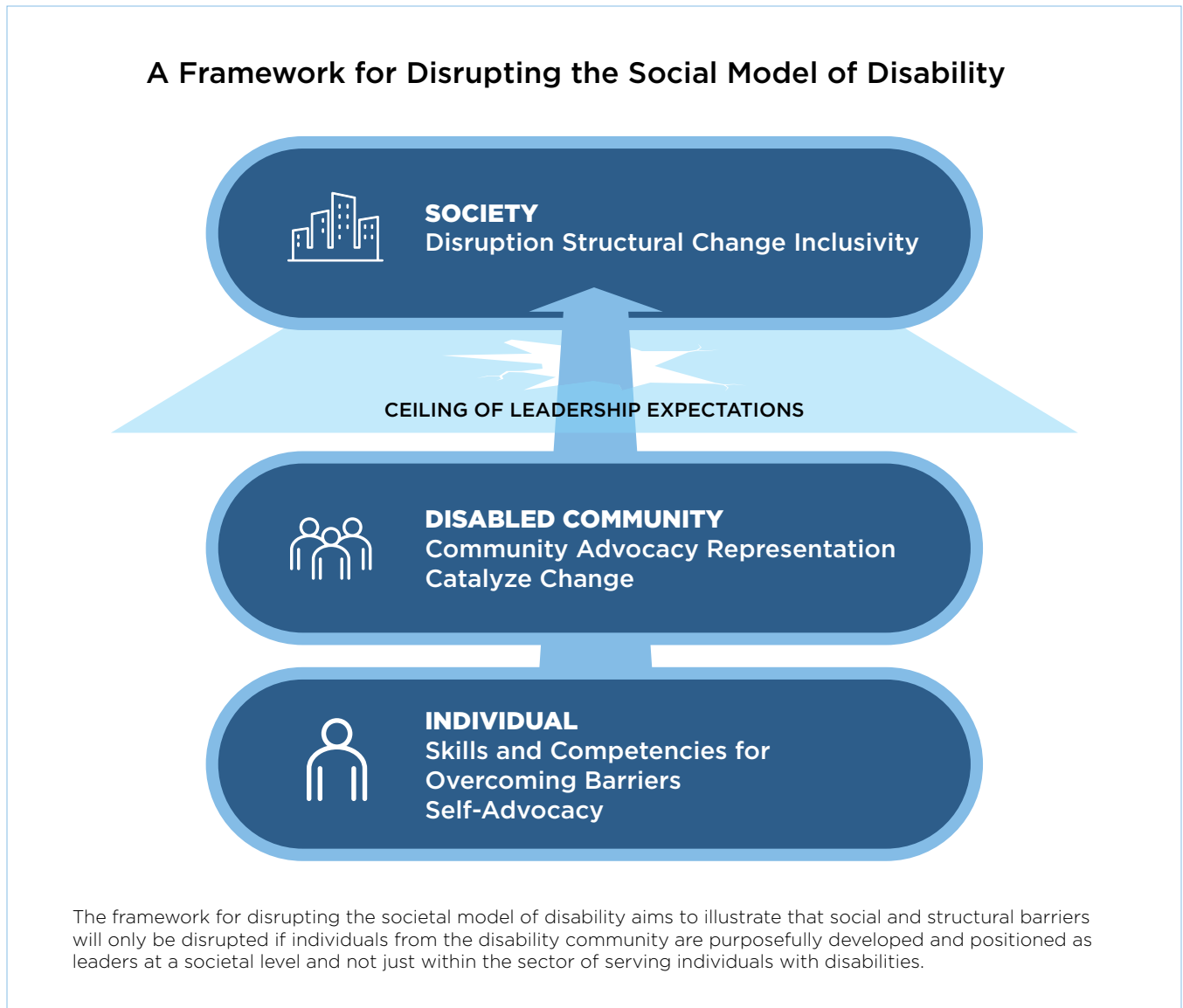
necessity of feedback to achieve the goals and objectives of each. The levels operate with their core values but establish "CHANGE" as the preeminent goal (Higher Education Research Institute, University of California, 1996). Leaders outside of the current systems have the opportunity to disrupt the status quo. As Crosby and Bryson state, "visionary leaders often bring to light what power and privilege obscures" (2005, p. 112).

To disrupt the fabric that underpins the medical and social models of disability, change must occur at the system and societal levels. As we have established through this literature review, current research and much of the available programming for those with disabilities generally address individual level (or self-advocacy) and only begin to address their role as advocates for their community of individuals with disabilities. The existing models fail to account for ways to pierce through the disability stigma ceiling placed on leadership expectations. Only rarely are disabled individuals seen as potential leaders outside of their representation of the disability community.

Therefore, our recommended framework to disrupt the social model of disability illustrates that social and structural barriers will only change if individuals from the disability community are purposefully developed and positioned as leaders at a societal level and not just within the sector serving individuals with disabilities. Addressing the underlying causes of societal and systematic barriers to participation for the disability community stands to positively impact the lives of many, advancing the objective of true inclusivity. As King et al. state, "disability leadership is distinct from other forms of leadership, in that it is often assumed by people in positions of

powerlessness and exclusion” (2023, p. 1165). The resultant clarion call is to establish robust pipelines to develop new leaders from the

disability community and unlock real, enduring change for the benefit of all people.

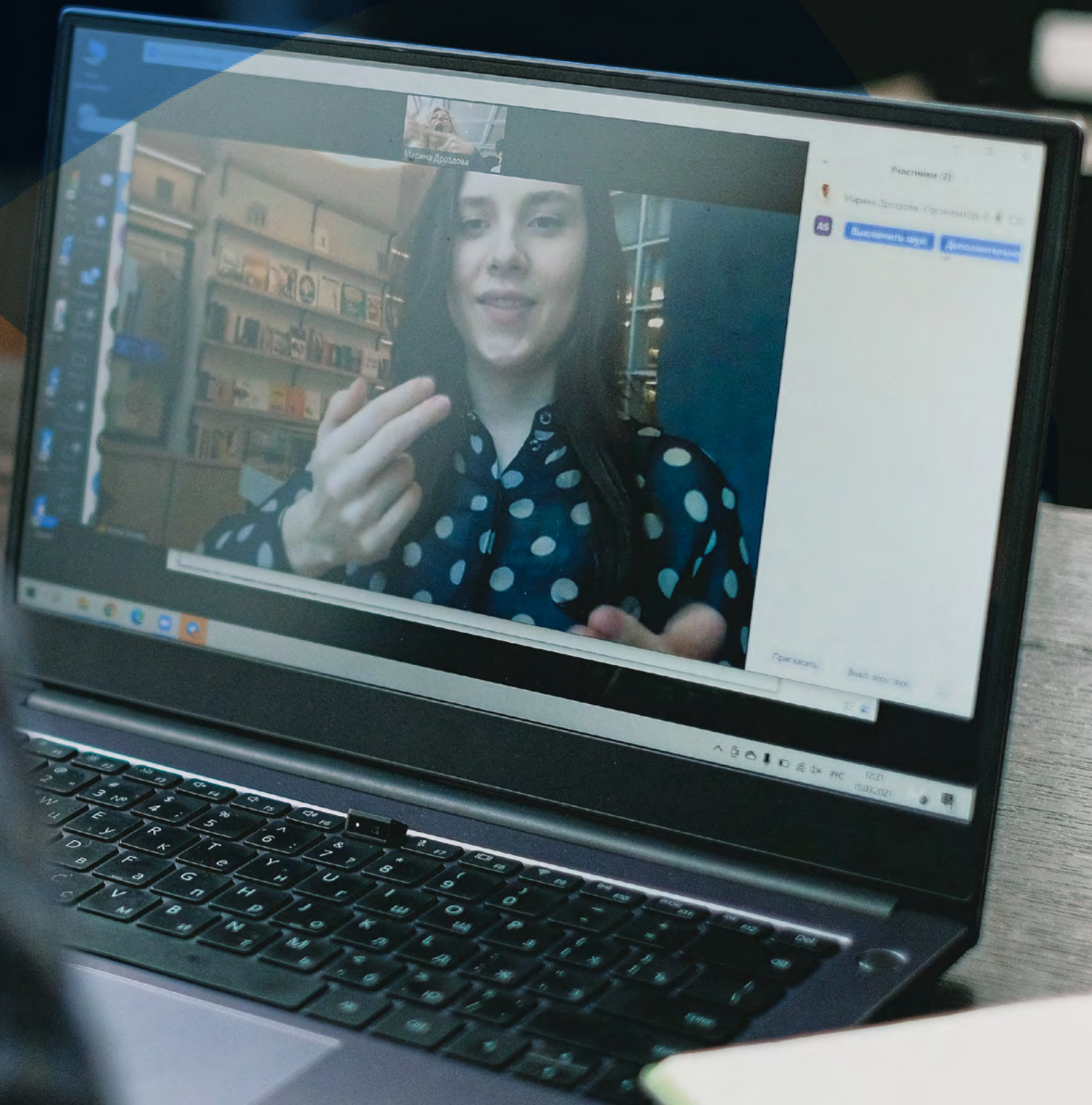


To address the problem of practice, this project supports the evaluation that FISA has launched using principles of program evaluation and qualitative research to assess the community’s needs. Throughout our work, both FISA Foundation and Disability Lead will participate and benefit from insights into the community

as well as deliverables that speak to the conceptual framework and support next steps with respect to proposed expansion into other cities using the FISA, SWPA-focused process as a model.

Project Questions

- 1. In what ways might FISA Foundation encourage more robust participation in their work from persons with disabilities in the SWPA region?**
 - a. What are current barriers to participation?**
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- 2. What adaptations, if any, are necessary to the Disability Lead model to serve the SWPA disability community?**
- 3. How might FISA Foundation establish and maintain support for a new disability-focused leadership development program in SWPA?**



V. Project Design

Data Collection Plan

FISA Foundation Data

FISA Foundation actively engages community members, facilitating interviews and focus groups, to gather evidence about factors which support and prevent opportunities for disabled persons. Due to FISA Foundation's extensive work, the research team gathered notes and recordings from these sessions. While FISA Foundation and Disability Lead teams have used their respective notes to inform their plans, they lack a systematic approach to coding and analyzing the data. Therefore, we worked with FISA Foundation to assemble the notes and recordings which served as the primary point of data collection. Additionally, to triangulate the feedback from these sources, we also gathered the minutes and notes from meetings of the Board of Trustees and the RACE + Disability Advisory Committee as well as notes and correspondence with other philanthropic groups such as the Heinz Endowments and the Pittsburgh Foundation.

Interviews were conducted with the Executive Director and Senior Program Officer. These interviews gathered their perspectives relative to the research questions based on their decades of experience with the SWPA Disability Community and other philanthropic partners. Interview questions for FISA staff, provided below, were derived from the project questions and the team provided prompts for additional explanation and specifics as appropriate.

1. What barriers have you observed that prevent disabled individuals from participating at the levels of society where systems and structures are maintained?
2. What factors currently support leadership participation by disabled individuals at community and society levels?
3. What have you learned about Disability Lead that you expect will work well in SWPA?
4. What differences do you see between Chicago and SWPA that will impact a program's success in SWPA?
5. What structures and supports are currently available to a new program such as Disability Lead in SWPA?
6. What organizations do you expect to play a role in launching the program? Describe the support you expect.

Each interview was conducted via Zoom, and included a minimum of two of the three researchers affiliated with this project. The interview session were recorded with permission from the participant and in accordance with applicable state law. The completed recordings were transcribed using Otter.ai for ease of review.

Disability Lead Data

Another primary source of data for this project is the program curriculum and collateral materials from Disability Lead. To assess any modifications that would be necessary to adapt the program to address specific needs identified in the SWPA region, we reviewed materials to become familiar with the extant program and how it aligns with the expectation and aspirations of this potential new market. Additionally, we gathered input through existing surveys of participants of Disability Lead's cohorts to assess what they identify as strengths and weaknesses of the program.

Document Analysis

All audio and meeting recordings were converted into written transcripts using Otter.ai. Transcripts, meeting notes, and minutes were coded for themes using Dedoose. A minimum of two team members read and coded each artifact to reduce bias and affirm inter-rater-reliability of coding practices. Review of literature and the conceptual framework suggested initial coding and identified several themes, identified below. Other themes emerged as the work was conducted. Due to the scope of this project, not all identified themes are included in this research output.



Photo courtesy of Kampus Production

VI. Data Collection and Analysis

Data Collection Process

The team scrutinized data from several primary sources. The majority of the data is in the form of existing documents from FISA Foundation and Disability Lead. The project team conducted interviews of FISA Foundation and Disability Lead staff as well as several members of the region's disability community. FISA Foundation provided 20 discrete assets of internal documents reflecting meeting notes and recordings completed over a 7-month period as they explored the Disability Lead program and curriculum and sought local feedback on interest and support for such a program in the SWPA region.

The team analyzed meeting notes in their existing form of text (Word) documents and used a coding scheme that we created to follow categories that we revised during planned meetings for this purpose. Each video recording was transcribed into a text (Word) document using Otter.ai, a web-based technology that uses artificial intelligence to convert speech into text transcription. Once all recordings were transcribed, the FISA Foundation data source comprised 159 pages of material. Additionally, the research team interviewed the senior program officer of FISA Foundation. The interviews were conducted via Zoom between December 2023 and February 2024, and the meetings were transcribed as above, using Otter.ai. Disability Lead provided materials from their current program, including rosters, results from conducted surveys, and the Workbook from their current Fellows program. The complete list of documents shared is included as Appendix C. For simplicity, the research team developed a naming convention for the portfolio of documents. This convention is used throughout this volume when referencing content contained within a specific document.

Validity Challenges – Data Collection

Given that FISA Foundation collected most of the data used in the analysis, one potential concern is that Foundation representatives may not have met with a sufficiently representative sample of individuals and organizations. We believe any concerns over this self-selected group are mitigated because the individuals and organizations were specifically selected for the influence over and knowledge of the respective groups they were chosen to speak on behalf of. FISA Foundation staff are highly knowledgeable of the region's disability community and related organizations and often serve as conveners to encourage and support inter-agency collaboration and communication, as well as working closely with government officials to advance the needs of this population.

Analysis Process & Rationale

As a research team, we collaborated on a research codebook. We treated the creation as an iterative process, starting with precoding whereby we engaged in unstructured reading of the data assets to immerse ourselves in the data, enhancing familiarity and generating potential codes. This process also serves as a check of our overall research design and literature review (Ravitch & Carl, 2021). Following this activity, using our project questions and literature review as a foundation, we developed a list of 28 codes, divided into two primary categories: barriers and enablers. Secondary categories were defined for each primary category. Barriers were expanded to three secondary categories: absence, perceptions, and presence. Enablers were expanded to two secondary categories: opportunities and presence. Each of these five secondary categories was further defined by the creation of tertiary categories, which make up the largest portion of the code

book. A third primary category, establish and maintain support, along with a list of secondary categories contributing to the same, rounds out the complete codebook. Definitions of each code were created as a research team to not only distinguish between codes, but to ensure clarity of their meaning and enhance inter-coder reliability between the researchers engaged in this project. The codebook was loaded into Dedoose (version 9.0.107), a web-based application widely used for mixed methods research where qualitative and quantitative data integration is desired along with robust data visualization. The code book may be found in Appendix A.

The research team divided the task of reviewing each document and coding notable ideas, comments, or expressed needs using our codebook. This process, called open coding, involves multiple rounds of reading. According to Ravitch and Carl, conducting multiple readings of data enhances the researcher’s familiarization and connection with the

data, allowing them to thoughtfully consider different foci and goals as well as identify key themes (2021, p. 265). During this process we determined that a separate codebook for each data set would be appropriate. Final versions of the code books may be found in the Appendices.

Data analysis proceeded as planned. As we developed the themes and codes for analysis, a natural evolution occurred as the themes were tied more closely to our research questions. The first coding activity took place as a team to ensure alignment and consistency of process. Then, each document was coded by one team member and reviewed by at least one other member to ensure inter-rater reliability. Dialogic engagement regularly occurred throughout the data analysis process. Questions or discrepancies identified by any single research team member were flagged and discussed by the collective team, and the agreed-upon outcome was applied accordingly.

DATA ANALYSIS PLAN

| Initial Coding Themes | |
|---|--|
| Unique to FISA Foundation Data | |
| Social nature of barriers to participation | Covering or passing behaviors and variation based on setting |
| Employer (lack of) supports | Existence (or lack of) mentorship opportunities |
| Educational system (lack of) supports | Representation (or lack of) disabled leaders |
| Identity threats (real and perceived) | Institutional support of disabled leadership |
| Unique to Disability Lead Data | |
| Supports available to the program in Chicago | Curricular components that address mentorship |
| Curricular components that address covering/passing | Program components that address representation |
| Organizational partners/supports | Opportunities for program enhancements or adjustments |

Photo courtesy of disabilitylead.org



Validity Challenges – Data Analysis

As we completed the coding process, we noticed an interesting trend. Among the data and codes, there exists a sameness of several of the barriers and the supports that need to be established and/or maintained, making it often difficult to differentiate between an existing problem (barrier) and/or a desired need for a positive outcome (support established or maintained).

This resulted in multiple dually coded items within the data assets. For example, if a barrier, or absence, was named as “lack of support” that sameness in the data showed up existing in the coding of what we found was also present: “exclusionary practices”.

We expect this challenge to be mitigated by the through line of our project questions in that what is needed for the program in terms of established and maintained supports should be informed by, and with the intent of, overcoming the existing barriers.

Results of Data Analysis

Through our analysis, we have identified data that directly addresses our research questions. The predetermined codes were well represented throughout the documents examined as illustrated in Appendix B. We identified emergent themes through discussion among the team which are further explored in the Findings and Recommendations section.

VII. Findings and Recommendations

Findings

Through our analysis, we have identified data that directly address our research questions and centers on several themes. While attributed to individual project questions, our findings reflect the interrelated nature of our research and may address multiple questions depending on one's interpretation. Participants named factors that prevent their participation in leadership and, in so doing also articulated essential mechanisms for making a new program successful and sustainable. Mapping the results to the most relevant project questions reveals the following:

Project Question 1: In what ways might FISA Foundation encourage more robust participation in their work from persons with disabilities in the SWPA region in order to disrupt for social change?

- a. What are current barriers to participation at the societal and systemic levels?
- b. What are current enablers to participation at the societal and systemic levels?

Participants shared appreciation for FISA's role as a force for disability rights in the SWPA region. In multiple conversations, participants commented on the trust the disability community has for FISA. More than one participant stated they do not expect FISA to do this work alone. A participant described the exploitative nature of other organizations' requests for their involvement and noted that this was not a concern with FISA. The prevalence of tokenism among institutions is well documented in the literature. McFadden and Downie (2018), referencing Arnstein (1969) said, "...forums, to which people with disabilities are commonly invited, are highly

tokenistic" (p196). Comments such as "it's not about filling a quota but what they can fully bring to the table" highlight a broader feeling of exploitation by members of the disability community (FISA-MN-14). Several stakeholders expressed concern over the expanded role in advancing a leadership development program that might overextend FISA, rendering it unable to give attention to the many projects in which it is currently involved. Concerning the inclusive and trusted role of FISA, a participant stated, "No one has ever considered me as a leader till I stepped into this space" (FISA-MN-12). Such comments were so pervasive that they bear recognition in our first overarching finding:

FINDING 1: FISA Foundation is a recognized, respected, and trusted advocate for the disability community in SWPA.

Participants in stakeholder focus groups affirmed the need for more deliberate leadership development and hinted at the causes of the reduced interest seen in recent years. As one participant noted, "We have this notion that the next generation of leaders will be cultivated and developed organically. But it's not true. We have to be really intentional about who gets to serve, who gets to lead, and we can create the diversity that we want to see" (FISA-MT-4). A participant also acknowledged that mainstreaming children in school has meant that individuals with disabilities are more involved with the peers they grow up with rather than with the disability community.

This participant noted that it makes it more challenging to engage them with disability issues because they are “engaged in broader issues” (FISA-MT-4). As another participant put it, “It’s kind of like stretching your arms around more and more people who wouldn’t typically be engaged because they didn’t have a developmental disability, or they weren’t in school for that” (FISA-MT-3).

Past movements for disability rights have capitalized on highly visible disabilities, with leaders such as Judy Heumann, a wheelchair user, advocating for physical accessibility leading up to the passage of the Americans with Disabilities Act (ADA). Between technological advancements and mainstream education, the siloed nature of disability advocacy groups may weaken their effectiveness and attractiveness for growing numbers of individuals living with disabilities. Stakeholders from the focus groups cited many local disability-focused groups and their individual efforts to prepare individuals with disabilities for advancement, including 21 and Able, an effort by the Parent Education and Advocacy Leadership (PEAL) Center. The PEAL Center is indicative of the type of efforts participants could name as currently ongoing – 21 and Able focuses on the transition from compulsory education into adulthood for individuals with various disabilities. It concentrates on self-advocacy and life skills.

Allegheny County, the largest county by population in SWPA, published a report on community resources in 2019 and cited at least 48 disability-specific organizations in Allegheny County alone. In addition to the entities named by the County, SWPA is replete with several hospital systems, multiple universities, and corporations, many of whom have resource groups or support offices for persons with disabilities. Participants in the various focus groups named organizations they were familiar with and the organizational initiatives that

may align with the proposed program. As one participant stated, “Disability constituencies just do not show up. Some orgs are focused on neuro diversity, others on other. It gets so narrow, there’s not a holistic organization” (FISA-MN-7). These comments highlight our second finding:

FINDING 2: The region is home to myriad disability advocacy groups with little to no coordination between organizations.

Adjei-Amoako (2016) called the lack of coordination among disability advocacy organizations a “barrier to promoting inclusive development” often leading to issues of inefficiency from duplication of efforts (p 873). FISA prides itself on playing the role of convener, which may not be able to drive change directly at the local government or corporate levels. Still, they commonly do what Trautmann often describes as “buy the coffee, call the meeting.” Participants’ comments on the value brought by FISA Foundation affirm the importance of this connective tissue and coordination that often advances disability-focused initiatives. As one participant stated, the region does not need “just another 501(c) (3) put into the mix” (FISA-MN-7). FISA has been more than just another entity in the region. FISA outperforms its small size by contributing to larger conversations. Through the practice of calling the meeting, FISA breaks down silos between disability organizations, hospital systems, corporations, and government agencies. Through these convenings, FISA marshals more than just its own resources to reshape the systems which bar disabled individuals from full and equal participation in society.

Project Question 2: What adaptations, if any, are necessary to the Disability Lead model to serve the individuals with disabilities in the SWPA?

Across the interview and focus group transcripts, there exists an ever-present awareness of the need for accessibility and financial support. Harkening back to Finding 1, the general sentiment is, again, that FISA cannot go it alone. Any program they develop and implement will need both committed personnel and capital, not only for its inception but, importantly, for its sustainability and growth. Additionally, FISA should consider accessibility in all aspects of a new program. To be sure, the questions of financial support and accessibility were raised in connection with several of our defined research codes, such as partnerships with local organizations, lack of support/accommodation, and lack of coordination between organizations/services, once again demonstrating the interrelatedness of our research questions.



In discussions on the need for partnerships with local organizations, one participant highlighted that from the outset, FISA is a source of limited philanthropic funding, providing resources through other charitable organizations and both community and corporate foundations (FISA-MT-5). It is the

awareness of and reliance on funding from additional sources that makes partnerships/sponsorships critical to long-term success. One participant in a meeting questioned whether “we have the will (enough support in terms of volunteer advisors and networkers; partnerships for success, funding); to raise funds” while acknowledging that identifying revenue sources will be a significant topic for discussion as many of the more prominent funders have become reluctant to provide financial support for programs requiring sustainable funding (FISA-MN-1; FISA-MN-2).

While the funding provides an opportunity, it also is viewed as an acknowledgment of individual value. As one participant remarked, “I get a lot of requests from corporates to have people...can you have people for a focus group? And I’ll always say, what’s your budget? And I get that? Oh, there isn’t one. So, the value of, you know, people’s time in which, I’m speaking to the choir here...” (FISA-MT-4). The lack of recognizing value is present in the literature where Rak and Spencer (2016) found that significantly fewer persons with disabilities served in community volunteer activities than non-disabled populations. Any new program designed by and for persons with disabilities should place adequate value on people’s time and talent. To presume that persons with disabilities are completely happy to just be included is an insult and would signal a complete lack of understanding of the community served.

We also find financial support concerns prevalent in association with the barrier of lack of support/accommodations. During the FISA and Disability Lead stakeholder meeting on February 6, 2023 (FISA-MN-4), a participant identified the barrier of “big costs to start-up” and said that the “disability community comes up short on cash and energy.”

In this same meeting, multiple components of accommodation barriers were identified, such as a lack of transportation, childcare, and Internet access. In other meetings, participants suggested that successful accommodation considerations would include addressing income limitations, including lost wages, offering multi-lingual support, and hosting program sessions during different times of day (FISA-MT-4). In an ideal program, “access and inclusion would not be an afterthought” (Shani Lasin, FISA-MN-7). The prevalence of concern throughout the data leads us to our third finding:

FINDING 3: Accessibility and financial support cannot be overemphasized.

This finding signals a desire for spaces, both physical and metaphorical, where socially constructed barriers to access have been deliberately and proactively removed. Particularly in a space designed to empower individuals with a disability to pursue leadership unabashedly, participants seek a clear pathway to participation that does not require their mental, physical, or emotional energy to overcome imposed barriers.

Project Question 3: How might FISA Foundation establish and maintain support for a new disability-focused leadership development program in SWPA?

We approach our third project question in search of factors that would enhance the community’s commitment to the success of a proposed new program. We expected to identify characteristics that contribute to psychological safety as well as suggestions for funding or other relationships that would position the new program for long-term organizational success. What we found was

a clarion call for interpersonal relationships that support advancement for non-disabled persons but are often lacking for disabled individuals. Differences in access to mentors frequently account for differences contributing to participation in teams (Edmonson, 2014).



In the disability community served by FISA, the desire for mentorship opportunities is high. Comments expressed in several meetings and focus group sessions punctuate the importance of mentorship. One participant stated, “Mentorship is incredibly important.” Another said, “I think that kind of like peer mentorship is really important among people with disabilities, and fostering those relationships is important. And I think, you know, connecting people to other people is really important.” (FISA-MT-4). In other meetings, participants echoed the desire/need for mentorship, expanding further expressing a need for “Role models that look like you, especially people of color.” and that it is “important to have visible leaders with disabilities so others can see themselves” (FISA-MN-14). The challenge for FISA lies in finding persons who are willing to mentor. During the same 15 June meeting, a participant asked, “There is a lot of talent. How do we find untapped talent?”

The mention of “untapped” is particularly salient as other conversations considered the current state of support. During the 15 June meeting, we also heard, “Josie and Rachel get tapped all the time, and they don’t know enough people for those opportunities.” The over-reliance on a small cadre of volunteers was a common refrain in the data. At another meeting, participants expressed, “It is the same small handful of people who get tapped over and over again; they are largely white, they largely have physical disabilities. And, and we need, we need to really build a pipeline of what our future looks like.” “Holly was somebody who had been tapped over and over again. ... I wonder if this is a group that’s like feeling like immensely feeling this pain of like, I’m tapped out. And we need we need new leaders.” (FISA-MT-5). These statements are cause for concern, and they are an indication of imminent burnout among valuable disability advocates.

The need to identify new talent is paramount. Challenges facing this effort exist due to a decades-long reluctance of individuals to share their disability identity or an unawareness of a disability identity. Despite recent progress, disability is still a relative newcomer to realm of identity politics where the focus on inclusion has largely been on visible identities (Iezzoni, 2000).



We found evidence of individual identity unawareness, covering, and resistance/denial. As one participant said, “Some people are discouraged to self-identify and don’t want to.” (Joni Swagger, FISA-MN-7). Another participant summed up the current resource gap as follows:

There are a lot of people in our community who live with chronic illness, not readily apparent disabilities, who may not even recognize that they’re a member of the disability community, who don’t know that there’s a fantastic civil rights movement of folks who’ve really fought for change, who are not connected, and not equipped to advocate for themselves or others. And so, a huge untapped pool of talent that we can draw on. And we know that we need to be as intentional as possible in addressing racial equity and other intersecting equity issues as we try to build and enhance pipelines of leadership (FISA-MT-2).

This statement lays bare the challenge faced by FISA in SWPA and guides us to our fourth finding:

FINDING 4: Opportunities for mentorship are minimal due to the lack of leaders in the community who have a disability identity.

FISA has collected feedback from the disability community that they want to see leaders openly leading with their disabilities. Without real-world examples of disabled leadership, it is difficult for a person with certain disabilities to imagine what it would look like to assume a leadership role. Participants are ready to see leaders embrace a disability identity instead of covering it in public and sharing their struggles only in private.

Recommendations

Based on our findings and our understanding of FISA's capabilities, as well as opportunities and limitations in the SWPA region, we suggest the following five recommendations.

RECOMMENDATION 1: FISA Foundation should leverage its trusted reputation as a convener for disability rights to mobilize institutional and political supporters.

This recommendation stems from FISA's long history in the region working to advance opportunities for women, girls, and persons with disabilities and is rooted in Findings 1 and 2. FISA's origin story may have its roots in noblesse oblige – a group of highly privileged white women giving back to the region where their husbands and families amassed wealth – but it has evolved into a trusted community asset led by the very populations it seeks to serve.

Reflecting on the Social Change Model of Leadership Development described in shaping our conceptual framework, we posit that FISA is in an ideal position to advance change by virtue of its existence outside of corporate and political structures that maintain the status quo (Higher Education Research Institute, University of California, 1996). As a private foundation run by an independent board of directors, FISA has a high level of freedom and flexibility.

FISA is also entirely agnostic when it comes to representing different categories of disability. FISA deserves its reputation of trust for a variety of reasons, including that it goes beyond serving only one disability identity. Intellectual disabilities are considered as valid as physical disabilities, and FISA has regularly supported all types of disability, both visible and invisible. FISA has also gained recognition as a foundation that promotes racial justice work, as evidenced by the RACE+Disability Advisory Committee and through deliberate grantmaking efforts.

In conversations with Executive Director Kristy Trautmann, FISA has already brought new funding partners to the table to support this initiative, including both the Ford and Heinz Foundations. In the documents provided by FISA Foundation, we examined notes from meetings with the mayor's office for example which showed early support for FISA's efforts to bring a new leadership program to the region and interest in continuing the discussion with additional representatives. Similarly, representatives from local hospital systems and universities spoke of opportunities to link their work with this initiative.

FISA's existing relationships in the region will serve as a foundation upon which to build the network of mentors, leaders, employers, and candidates for the program. Inherent within this new endeavor is a risk to FISA's reputation and brand. As a small, nonprofit organization, FISA wields significantly less power than many of the corporate or healthcare system partners who will be critical to this program's success. Several articles warn against the pitfalls of cross-collaboration of nonprofit organizations with for-profit entities, citing threats to mission integrity and legitimacy due to misaligned foci (Bendell, 2020; Herlin, 2015). The literature does not generally address partnerships among multiple nonprofit organizations.

However, the challenges of misalignment may still be a factor as each entity aims to support a particular sector of the disability community. For this reason, we would include within this recommendation a suggestion that FISA carefully consider the alignment of values with any key partners and continue to center FISA and Disability Lead as the standard bearers.

Finally, we offer one note on FISA's role and future organizational structure for a new program. As previously mentioned, participants noted that FISA cannot do this work alone in its current anatomy of just four employees. If the following steps involve Disability Lead hiring additional personnel to lead the SWPA expansion of the program, FISA's support for those individuals will be critical. As new, local leadership is eventually identified to run this program, FISA should continue to serve alongside to introduce the program leadership to all types of stakeholders. FISA's role in bridging the societal level of our Framework for Disrupting the Social Model of Disability is critical for aligning the opportunities to shatter the ceiling of leadership expectations for persons with disability.

RECOMMENDATION 2: FISA should secure commitments and support from key institutional partners.

Concerns over sustainable funding sources for the new disability-focused leadership development program emerged in notes and transcripts from multiple meetings. The desire to fully fund participants by removing obstacles to participation in the program requires significant financial support, particularly in the early days of the new program.

The Disability and Philanthropy Forum reports that only 2% of foundation grants in the United States focus on disability (2023). The overwhelming majority, 94%, of funding goes toward disability services and supports, further leaning into the medical model of disability while only investing 6% towards disability rights and social justice, which would impact the social model of disability (Disability and Philanthropy Forum, 2023). This vast gap indicates a meaningful opportunity for foundations to redirect giving toward efforts such as the proposed program, which has the potential to disrupt systems of oppression. FISA breaks from the model of the foundations just described and can leverage this new opportunity to encourage other foundations to do the same – promoting programming designed to lessen the ultimate need for services and support in a more just society.



Broadening the support for the foundation in the form of corporate partners, hospital systems, and universities will, in turn, represent fertile resources in the SWPA region for financial and other resource commitments. This will provide sustainable sponsorship for a new program.

FISA should continue to “buy the coffee, call the meeting” to build interest and secure verbal and, later, written commitments. Throughout the focus groups and meetings, participants repeatedly cited the large local universities and hospitals as places with the “weight” that organizations carried in the community and also resources their offices of disability use to support people. Several of the individuals with whom FISA met with work for the universities and hospitals and each expressed interest and willingness to participate.



The universities, in particular, can provide a wealth of resources, such as physical space to host program sessions as well as recruit potential program participants. Similarly, hospitals and universities have employees dedicated to disability support who can lobby their leadership to commit resources.

The final group that will be critically important is corporate partnerships. Due to the risks identified in the first recommendation, we recommend caution with sponsorships or naming rights. However, corporations present an opportunity to work with human resource offices and employee resource groups. These relationships would provide prospective participants but would also support the development of employment pipelines and

other workforce development strategies that would be enhanced by seeing disabled job applicants in a new light through participation in the program.

Each of the groups described in this recommendation is also a critical partner for identifying individuals with disabilities who can serve as mentors in the program, leading us to recommendation number three.

RECOMMENDATION 3: FISA should identify strong mentors from the greater SWPA region and cultivate compelling examples of success while leading with one’s disability.

Providing expansive mentorship requires additional qualified persons to serve as mentors. The word additional is crucial to this recommendation as our data lays bare the strain on FISA’s existing supporters. Introducing new persons into the fold is likely to result in both tangible and intangible benefits for FISA.

Obviously, more support will lighten the burden, but the additional support may also inject renewed vigor into the work across the organization.

Mentorship serves as a valuable opportunity for individuals seeking professional development and advancement. The experience often provides support, beneficial on-the-job education, confidence, and increased visibility in an organization. Beyond skills improvement, Shek et al. (2015) suggest that mentoring also works as a social support. In the social realm, mentorship directly contributes to an individual’s identity, “cultivating a sense of professional self” (Shek, 2015, p. 351) and providing pathways to friendships both inside and outside the organization.

The data that led to Finding 4 prompts this recommendation. FISA's existing supporters expressed confidence that there are many industry professionals with disabilities in the region who could potentially be strong mentors. The concern is that these individuals are either discouraged from revealing their professional identity or are unaware they possess a disability identity. FISA should tread lightly but intentionally by engaging its current network of supporters in conducting personal outreach to discuss FISA's mission and learn more about where people are in their identity. Prior to outreach, FISA must establish a common language and guidelines for their mentorship program, clearly defining elements such as required training, engagement expectations, and time commitment. This is important to mitigate reluctance to volunteerism stemming from misunderstanding. Through focused personal networking and information campaigns, the web of supporters is likely to grow.

Finally, when mentor/mentee connections are made, FISA should closely monitor and record the experiences through written case studies. The program should capture and highlight both the mentor and mentee experiences and benefits to the participants and organizations, particularly in terms of demonstrated leadership as this supports the Disruption of the Social Model of Disability Framework we present. Case studies like these will be a valuable commodity for FISA's continued outreach to ensure program sustainability.

RECOMMENDATION 4: FISA should include accommodations as a base expectation in program components.

From the outset, FISA must employ elements of design justice in its newly created leadership

development program. Participants identified inaccessibility to program participation as a significant barrier in the research data. The significance of the accessibility and financial support issues revealed in Finding 3 critically informed this recommendation. FISA can overcome this challenge and guarantee that its program operates in a manner that eschews typical systems of structural inequality by centering persons with disabilities in their effort.



In her book, author Sasha Costanza-Chock (2020) defines Design Justice as “a framework for analysis of how design distributes benefits and burdens between various groups of people.” (p. 23). More broadly, the concept of design justice is a community of practice, a movement that seeks to challenge the admirable intentions of accessibility, pushing designers to think beyond the idea of “good enough” to create opportunities for liberation from barriers while avoiding unintentionally replicating existing systemic inequalities. Through life experience, persons with disabilities learn innovation and problem-solving skills to navigate an ableist world. By centering their experience in the design of the new program, FISA ensures that the impact on the disability community is prioritized.

In terms of physical spaces, Steel et al. (2018) recommend a three-step approach to achieving disability-centered design justice, which includes a tour of the spaces, a design activity, and brainstorming sessions focused on identifying opportunities for accessibility improvements. Once again, FISA will need to “buy the coffee” and bring both individuals and organizations together to maximize the impact of accommodation initiatives.

RECOMMENDATION 5: FISA should ensure all financial barriers to participation are addressed, including lost wages.

Based on our model of disruption, in order for people with disabilities to be purposely developed and positioned as leaders at a societal level, FISA must aggressively seek monetary and infrastructure support from benefactors across the region to mitigate financial barriers preventing program participation. Through focus groups and interviews, potential participants in a new leadership development program expressed two things in concert. One, a strong interest in participation, and two, a concern about the need for financial accommodations to enable participation.

To overcome the financial barriers, FISA should increase its focus on partnerships with business sector organizations. According to Bendel (2010), “If we are to achieve the massive changes in economy and society to address the myriad global challenges we face, we will need business professionals to be active members of a social movement to transform economies” (p.3). The wide variety of industry sectors present in the Greater Pittsburgh metro area, accompanied by some long-standing, robust endowments and the current social/

political environment encouraging corporate social responsibility (CSR), provides FISA with multiple avenues of opportunity and a compelling entry argument for seeking support.

Participants in focus groups and meetings referenced a variety of accommodations ranging from physical access to spaces and interpreter services to more fundamental issues of access, such as lost wages and transportation issues. The Disability Lead program curriculum uses in-person as well as Zoom sessions to minimize concerns over transportation. As FISA develops initial program budgets, FISA should consider whether there can be scholarships or other means to provide financial stipends for participants where it is necessary for participation.

Each of the preceding recommendations reflects an opportunity for FISA to lead social change while remaining true to the foundation’s values and mission of championing safety, justice, equity, and inclusivity. By building a coalition of advocacy with both institutional and political supporters in the SWPA region, FISA can expand their network of individual supporters and identify qualified individuals to work as mentors. Further, by ensuring appropriate accommodations, centered around the individual, FISA can disrupt the status quo of limitations on leadership within the disability community through their proposed leadership development program. Ultimately, armed with newly developed skills and competencies, disabled leaders are prepared to lead with their disability, breaking through the glass ceiling of leadership expectations exhibited in our Framework, and initiating positive disruption to elicit long-overdue social change.

VIII. Conclusion

The case for disability leadership in SWPA is strong. As we have established through careful review of the extant literature, current models of disability help to illustrate limitations imposed on disabled persons but stop short of articulating ways to break beyond those limits to disrupt systemic structures keeping them in place. Through our conceptual framework, we articulated a call to action to push beyond self-advocacy and limited leadership opportunities within the disability community for integration of disabled leaders at all levels of society. Our research established that absent interventions, persons with disabilities lack or are denied access to opportunities to break away from expectations limiting leadership potential.

FISA recognized the shortage of emerging leaders in the region and identified a potential solution in the Disability Lead model. The Foundation then proceeded to invest significant time and energy in gathering the input of the disability community to ensure interest and commitment to the potential endeavor. Our examination of the robust feedback provided deep insight into the thoughts and desires of the community. We commend FISA and Disability Lead for their commitment to community-based solutions rather than imposing solutions that are insufficiently informed by the community's funds of knowledge. The process undertaken by FISA Foundation and Disability Lead exemplifies an asset-based approach to problem solving. Their approach aligns with our understanding of the literature and supports the conceptual framework.

Stakeholders interviewed by FISA shared key insights openly and appeared willing to support a new disability focused LDP in the region. As our findings revealed, FISA is well positioned as a trusted partner to bring a new

program into being with the support of the community. FISA positions itself as a convener, an organization bringing various groups together to tackle sticky problems. This role appears critical to establishing a new LDP, supported by the wide range of key players essential to its operation. Disability Lead brings its reputation and credibility to the equation as well. As an organization of, by, and for disabled individuals, Disability Lead's model centers on relationships and mentoring that our findings revealed are in desperate need.



Throughout our research, we also heard concerns over accessibility and tokenization. Our findings and recommendations reflect the importance of accessibility as a central construct rather than an afterthought. Our perspective on accessibility extends beyond accommodations for access to physical space or alternate delivery modalities. We heard loud and clear that unpaid, emotional labor has long been a burden of those asked to represent the disability community, a common treatment of marginalized populations. Therefore, we broaden accessibility to include mechanisms which financially support participants where necessary and expand beyond tokenizing disabled persons.

FISA and Disability Lead can provide resources and access, but centering the disability community as leaders, role models, and mentors will help to realize the highest standards of inclusion and provide the appropriate safe space for participants to explore their own identity.

FISA and Disability Lead are poised at the beginning of a community-centered process to disrupt the social structures that impede full participation by the disability community. Our research suggests that this effort should continue, with FISA playing a lead role in the region.

As FISA and Disability Lead continue to gather corporate, foundation, and government support for the program, both parties seem aware of the need to maintain and sustain community engagement, which will occur through a steering committee of persons with disabilities in the region. This committee will be of critical importance – to achieve the mandate “nothing about us without us,” FISA must continue to be led by the voices of the community. If the first steps FISA has taken are any indication, they are well on their way toward mobilizing the next generation of “us.”



Photo courtesy of disabilitylead.org

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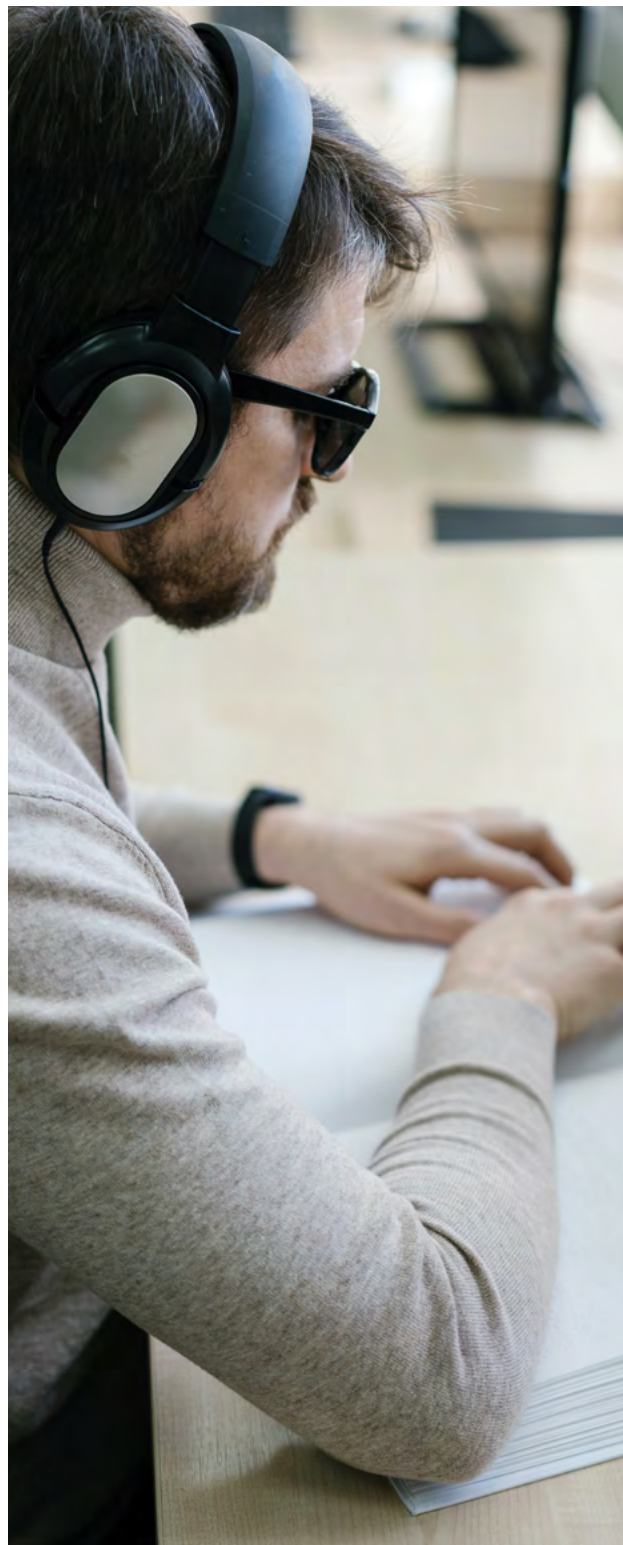


Photo courtesy of Mikhail Nilov

Appendix A

| PROJECT QUESTIONS | THEMES |
|---|--|
| <p>1. In what ways might the FISA Foundation encourage more robust participation in their work from persons with disabilities in the SWPA region?</p> <p>a. What are current barriers to participation?</p> | <p>Absence of supports, lack of knowledge/awareness of opportunities, lack of qualified personnel, coordination between services/organizations, authentic inclusion</p> <p>Presence of racism, ableism, red tape, arbitrary rules, exclusionary practices, dismissive responses, tokenization</p> <p>Perceptions of disability - monolithic approach, imposed limitations</p> |
| <p>b. What are current enablers to participation?</p> | <p>Presence of foundations and nonprofits in the region, rich educational opportunities (HE, School for the Deaf, etc.), growing political support, access to multiple medical systems for care</p> <p>Opportunities within HHS nonprofits for leadership at the community level</p> |
| <p>2. What adaptations, if any, are necessary to the Disability Lead model to serve the SWPA disability community?</p> | <p>Regional versus city-based, infrastructure (e.g. accessible transportation, overnight accommodations, technology (computer, WiFi)</p> <p>Need to promote and inform is higher as a nascent program</p> |
| <p>3. How might the FISA Foundation establish and maintain support for a new disability-focused leadership development program in SWPA?</p> | <p>Marketing campaign</p> <p>Partnerships with other local organizations and foundations</p> <p>Hire additional personnel - ideally with disabilities</p> <p>Buy the coffee call the meeting, storytelling</p> <p>Corporate sponsorships linked with workforce development initiatives</p> <p>Emphasize diversity of disability and identity in employees, instructors, mentors, participants.</p> |
| <p>OTHER</p> | <p>Quotable Items for Final Document</p> |

| FISA DOCUMENTATION CODES | | DISABILITY LEAD DOCUMENTATION CODES |
|---|--|-------------------------------------|
| <ul style="list-style-type: none"> • Lack awareness of opportunities • Lack of authentic inclusion • Lack of coordination between organizations/services • Lack of qualified providers/personnel • Lack of support/accomodations | <ul style="list-style-type: none"> • Program components that address representation • Program components that address passing/covering behaviors | |
| <ul style="list-style-type: none"> • Presence of bureaucracy • Presence of dismissive responses • Presence of exclusionary practices • Presence of racism/ableism • Presence of tokenization | | |
| <ul style="list-style-type: none"> • Identity concerns, needs to cover/hide identity • Perception of disability as a monolith • Presence of imposed limitations | | |
| <ul style="list-style-type: none"> • Presence of schools and other educational opportunities • Presence of foundations and nonprofits • Presence of multiple medical/hospital systems • Presence of support from political officials | | |
| <ul style="list-style-type: none"> • Opportunities for leadership w/in local disability organizations | | |
| <ul style="list-style-type: none"> • Providing transportation or other accommodations • Serving a region versus serving a large metropolitan city | <ul style="list-style-type: none"> • Supports available in Chicago | |
| <ul style="list-style-type: none"> • Need to establish trust and awareness as a new organization | <ul style="list-style-type: none"> • Opportunities noted for enhancement to the DL Model | |
| <ul style="list-style-type: none"> • Marketing and promotional campaign | | |
| <ul style="list-style-type: none"> • Partnership with local organizations | | |
| <ul style="list-style-type: none"> • Need for new personnel who identify as disabled | | |
| <ul style="list-style-type: none"> • But the coffee, call the meeting, tell the story • Need for transparent communication | | |
| <ul style="list-style-type: none"> • Corporate sponsorships for workforce development | | |
| <ul style="list-style-type: none"> • Emphasize diversity of both disability and identity | | |
| <ul style="list-style-type: none"> • Pull quotes | <ul style="list-style-type: none"> • 36 - Pull quotes | |

Appendix B Code Usage by Document Source

| | DISABILITY LEAD | FISA | INTERVIEWS |
|---|-----------------|------|------------|
| Adaptations | | | |
| DL Opportunities to enhance the program | 0 | 0 | 0 |
| DL Supports available in Chicago | 0 | 0 | 0 |
| Need to establish trust and awareness as new organization | 0 | 34 | 3 |
| Providing transportation or other accommodations | 0 | 6 | 3 |
| Serving a region vs serving a city | 0 | 22 | 0 |
| Barriers_Absence | | | |
| DL Program components that address passing/covering | 1 | 0 | 0 |
| DL Program components that address representation | 4 | 0 | 0 |
| Lack awareness of opportunities | 0 | 25 | 0 |
| Lack of authentic inclusion | 0 | 46 | 6 |
| Lack of coordination bw orgs/services | 0 | 43 | 1 |
| Lack of qualified providers/personnel | 0 | 39 | 2 |
| Lack of support/accommodations | 0 | 38 | 9 |
| Barriers_Perceptions | | | |
| Identity | 0 | 55 | 1 |
| Perception of disability as a monolith | 0 | 32 | 2 |
| Presence of imposed limitations | 0 | 28 | 2 |

| | DISABILITY LEAD | FISA | INTERVIEWS |
|---|-----------------|------|------------|
| Barriers_Presence | | | |
| Presence of bureaucracy | 0 | 25 | 1 |
| Presence of dismissive responses | 0 | 4 | 2 |
| Presence of exclusionary practices | 0 | 27 | 0 |
| Presence of racism/ableism | 0 | 20 | 0 |
| Presence of tokenization | 0 | 13 | 3 |
| Enablers_Opportunities | | | |
| Opportunities for leadership w/in local disability orgs | 0 | 31 | 0 |
| Enablers_Presence | | | |
| Presence of educational opportunities | 0 | 37 | 1 |
| Presence of foundations and nonprofits | 0 | 26 | 2 |
| Presence of multiple medical systems | 0 | 8 | 0 |
| Presence of support from political officials | 0 | 23 | 0 |
| Establish_Maintain_Support | | | |
| Buy the coffee call the meeting tell the story | 0 | 34 | 0 |
| Corporate sponsorships for workforce development | 0 | 66 | 0 |
| DL Organizational partners in Chicago | 3 | 0 | 0 |
| DL Program components that address mentorship | 4 | 0 | 0 |
| Emphasize diversity of both disability and identity | 0 | 39 | 0 |
| Marketing & promotion campaign | 0 | 37 | 0 |
| Need for new personnel who identify as disabled | 0 | 55 | 2 |
| Partnership with local organizations | 0 | 82 | 1 |
| Transparent communication | 0 | 24 | 2 |

Appendix C - Document Catalog

| REFERENCE ID | SOURCE | DOCUMENT DESCRIPTION |
|--------------|--------|---|
| FISA-INT-1 | FISA | Andrea_otter_ai.docx |
| FISA-MN-1 | FISA | 01 31 2023 Stakeholder mtg for DL and FISA.docx |
| FISA-MN-2 | FISA | 2 01 2023 Funder mtg for DL and FISA.docx |
| FISA-MN-3 | FISA | R + Disability Committee Meeting Minutes 11 09 22.docx |
| FISA-MN-4 | FISA | 02 06 2023 Stakeholder mtg for DL and FISA.docx |
| FISA-MN-5 | FISA | Kerry Stith PNC followup conversation on DL.docx |
| FISA-MN-6 | FISA | DON and DL.docx |
| FISA-MN-7 | FISA | Disability Lead Stakeholder Meetings Dec 13 2022.docx |
| FISA-MN-8 | FISA | Shona Eakin TRPIL Vforl.docx |
| FISA-MN-9 | FISA | UPMC intro to DL.docx |
| FISA-MN-10 | FISA | 02 09 2023 Stakeholder meg for DL and FISA.docx |
| FISA-MN-11 | FISA | Lisa Frank in Mayor Gainey admin about DL on 3 1 23.docx |
| FISA-MN-12 | FISA | 05 23 2023 Stakeholder met for DL and FISA.docx |
| FISA-MN-13 | FISA | 05 18 2023 Stakeholder mtg for DL and FISA.docx |
| FISA-MN-14 | FISA | 6.15 Disability Lead Creative Brainstorming.docx |
| FISA-MT-1 | FISA | TRANSCRIPT - Recording 2nd half of June 13 2023 DL Champions mtg.docx |
| FISA-MT-2 | FISA | TRANSCRIPT - Recording of Zoom meeting w employers on 04 26 2023.docx |
| FISA-MT-3 | FISA | TRANSCRIPT - Feb 9 2023 Stakeholder mtg for DL and FISA.docx |
| FISA-MT-4 | FISA | TRANSCRIPT.01 31.2023 stakehold mtg DL and FISA.docx |
| FISA-MT-5 | FISA | TRANSCRIPT-Feb 6 2023 stakeholder mtg.docx |

Naming Convention Logic/Key

FISA=FISA | DL=Disability Lead | INT=Interview | MN=Meeting Notes | MT=Meeting Transcript | DOC=Document

| REFERENCE ID | SOURCE | DOCUMENT DESCRIPTION |
|--------------|--------|--|
| DL-DOC-1 | DL | 2022 FELLOWS WORKBOOK PDF.pdf |
| DL-DOC-2 | DL | How To Guide.docx |
| DL-DOC-3 | DL | Committee Overview_ForMembers.docx |
| DL-DOC-4 | DL | Neon Directions and Definitions.docx |
| DL-DOC-5 | DL | Interest Form Email.docx |
| DL-DOC-6 | DL | Disability Lead- Expansion Projecct Scope FINAL.docx |
| DL-DOC-7 | DL | Needs Assessment Conversations.xlsx |
| DL-DOC-8 | DL | DL Presentation 10-10 data presentation.pptx |
| DL-DOC-9 | DL | Disability Lead Grant Letter from FISA Foundation.pdf |
| DL-DOC-10 | DL | export (31).xlsx - Roster of Civic Connection |
| DL-DOC-11 | DL | export (32).xlsx - Roster of Disabilty Lead participants |
| DL-DOC-12 | DL | Expansion Workflow.docx |

Naming Convention Logic/Key

FISA=FISA | DL=Disability Lead | INT=Interview | MN=Meeting Notes | MT=Meeting Transcript | DOC=Document

