

San Francisco Department of Aging and Adult Services

San Francisco Disability Community Cultural Center

FINAL REPORT



Prepared by the Paul K. Longmore Institute on Disability, May, 2019



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About the Paul K. Longmore Institute on Disability

Launched in 1996, the <u>Paul K. Longmore Institute on Disability</u> is a Research Service Organization established by San Francisco State University to promote collaboration, share the results of scholarly research and creative activities, and carry out public service programs related to the field of disability. It strives to create a world where everyone believes that society is better because of disabled people. The Longmore Institute studies and showcases disabled people's experiences to revolutionize social views. Through public education, scholarship, and cultural events like <u>Superfest</u> <u>Disability Film Festival</u> and its highly-regarded <u>Patient No More exhibit</u>, the Institute shares disability history and theory, promotes critical thinking, and builds a broader community.

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From the outset, we were guided by our clients' concern at the Department of Aging and Adult Services "that you hear from everyone." For this reason, we are deeply grateful to every single disabled person who helped us on this journey, whether by participating in the survey, a focus group, a leader interview, or by helping spread the word about our efforts.

Our work with creative, thoughtful people totally modeled the proposed Center's goal that people with disabilities build new connections and community rooted in useful, critical feedback and laughter along the way. Special thanks to our Leadership Committee as well as the dedicated team at the Department of Aging and Adult Services, and notably Executive Director Shireen McSpadden. Heartfelt gratitude too to Nicole Bohn, Director of the Mayor's Office on Disability, who built the bridges that allowed us all to come together around the idea of the transformative power of disability culture for people with disabilities.

Additionally, we would like to thank the leaders of San Francisco's cultural and community centers, as well as disability organizations that shared their expertise and expressed their enthusiasm for the future Center.

Cathy, Emily, and Christine

Glossary of Terms

Term/Acronym	Definition		
Ableism	The discriminatory belief that people who are non-disabled are better than people with disabilities, and the structures of power that reinforce that belief.		
Aging and Disability Resource Center (ADRC)	One-stop shops for community members to find assistance in accessing services and resources, so that individuals are more aware of their rights and can assist community members in living independently in their community.		
Barriers to Access	Factors in a person's environment that, through their absence or presence, limit functioning and exclude people with disabilities. In addition to physical impediments, people with disabilities can be limited by policies, programs, social and bureaucratic structures, cultural beliefs, and attitudes.		
Department of Aging & Adult Services (DAAS)	This department of the City and County of San Francisco coordinates services for older adults, veterans, people with disabilities, their families, and caregivers to maximize safety, health, and independence.		
Disabled People/People with Disabilities	While some call for using person-first language ("people with disabilities") as a way to reduce stigma, others prefer identity-first language ("disabled people") in order to show that many disabled people take pride in their identity as a disabled person and see it as central to who they are. We have deliberately used both terms "people with disabilities" and "disabled people" interchangeably.		
Disability Communities	The population of people with disabilities is comprised of various sub-communities of people with specific disability types. Because these sub-communities are so diverse, we refer to them collectively in the plural and avoid suggesting there is a uniform "disability community."		
Disability Community Cultural Center (DCCC)	The working title for the proposed new community cultural center for people with disabilities who live or work in San Francisco.		

Term/Acronym	Definition		
Disability Justice	Disability justice is a political understanding of disability and ableism that goes beyond securing rights for individual disabled people, toward achieving collective human rights for all. Initiated by white trans people and disabled people of color, this framework affirms the whole person, with particular attention to the impact of intersecting identities. It calls for systemic change so that basic needs are understood in relationships of interdependence and cooperation rather than competition and individual striving.		
Intersecting Identities	Because injustice comes from multiple sources of oppression, each person's unique combination of disability and race, class, gender identity, sexual orientation, religion, and other identity markers creates the circumstances of their life, including their visibility and access to power. People who are members of multiple marginalized communities are often referred to as having intersecting identities.		
Latinx	Latinx is a gender-neutral term that describes a person or people of Latin American origin or descent, which we use in place of Latino/Latina.		
LGBTQIA+	Recognizing that there is a spectrum of sexual orientation and a spectrum of gender, these letters refer to persons who identify as lesbian, gay, bisexual, transgender, queer, intersex, and asexual. The "+" indicates the way that this community continues to expand and evolve.		
Older Adults	Adults aged 65 or older, who are also referred to as seniors.		
People of Color (POC)	Persons who are not white or of European descent.		
Transition-Aged Youth (TAY)	Young adults, aged 18–24, who are making the transition to adulthood.		
Younger Adults	Adults aged 18–64, who are not yet considered seniors.		

EXECUTIVE SUMMARY

Under the direction of the San Francisco Department of Aging and Adult Services, the Paul K. Longmore Institute on Disability surveyed and developed ideas for the nation's first city-run center devoted to disability culture. We established a Leadership Committee comprised of diverse local leaders in the disability field, all of whom are people with disabilities, who guided us through an eleven-month development project to assess not just the need, but also the dreams of people with disabilities who live and work in San Francisco.

The first phase began with a review of the cultural landscape in which the new center will be built. This involved exploring recent data about the city's aging and disabled populations as well as learning about the complex web of existing services. We also conducted a literature review of disability studies scholarship and visited existing cultural centers for other minority populations in San Francisco to understand the impact that culture can have on marginalized peoples. Ultimately, we found strong examples that, in combination with service provision, demonstrate the need for culture in closing equity gaps.

In the second phase, the Project Team and Leadership Committee surveyed people with disabilities throughout the city, held focus groups with disabled people who are from marginalized groups, and interviewed local disability leaders to identify the biggest problems and dreams of San Franciscans with disabilities.

Bottom line: our research among people with disabilities, along with their caregivers, families, and allies, revealed overwhelming support for a San Francisco Disability Community Cultural Center (DCCC, the Center). The fact that more than half of survey respondents asked to be added to a mailing list for updates on its progress, and more than a quarter of respondents want to volunteer once it is open or serve on an advisory board further underscores the excitement around the Center.

While there was general enthusiasm for all potential goals suggested for the DCCC, three rose to the top: bringing together diverse people with disabilities, promoting social justice for people with disabilities, and celebrating disability arts and culture. Indeed, participants were hopeful that the new Center could help change what

many believed to be a climate that does not serve their best interests, despite San Francisco's reputation for progressiveness. Central themes that surfaced in the focus groups were discrimination, social isolation, and a desire for greater social justice and advocacy for people with disabilities. Many participants noted frustration with feeling misunderstood by the general population and even the leadership of people with disabilities, where they felt those from their identity categories were rarely represented in positions of power.

When they dreamed about what the Center might bring, participants across the board felt strongly that it be "for us, by us," where people with disabilities (including those further marginalized by race, LGBTQIA+ identity, veteran status, homeless status, or age) own the space in ways that include volunteering, employment, and participating on the Center's advisory board.

For disabled people who struggle with barriers to access, low self-esteem, and social discrimination, the idea that they are actually a social minority with a proud history rather than passive patients awaiting a cure has been buoyed by a vibrant disability culture that is increasingly seen as essential to disability rights.

The proposed DCCC will address several of the unmet needs identified in the 2018 Department of Aging and Adult Services (DAAS) Community Needs Assessment. By providing a dedicated, welcoming place where people with disabilities can gather and develop a shared culture, the Center will foster self-esteem and feeling valued. Moreover, educational, artistic, and social networking opportunities will bring diverse people with disabilities together to access resources, advance social justice, and foster disability culture, community, and pride.

Survey results and in-depth discussions with disabled people who live and work in San Francisco indicated that all DCCC programs and services must provide a safe and accessible place where they feel they belong. They asked that center programming and activities include:

- centralized information, referral, and assistance services
- advocacy training
- opportunities for creative expression
- socializing and developing personal relationships
- employment and leadership opportunities
- education about disability and disability history
- a focus on fostering disability culture, identity, and pride

In addition, to integrate people with disabilities more fully into broader San Francisco society, the DCCC may also provide educational and cultural activities that present disability in a more positive light to the general public and encourage access and public support of policies and programs that benefit people with disabilities and protect their civil rights.

Determining the Center's location and design, and deciding upon the specific services and activities it should offer will be part of the next phase of the DCCC project. This will be completed by an organization chosen in a competitive bidding process run by DAAS guided by the research provided in this Longmore Institute report.

INTRODUCTION

Since the 1970s and 1980s, an increasingly vocal minority of disability rights advocates, community leaders, and scholars have come to understand disability as part of the human condition, much like being female, LGBTQIA+, or a person of color. They resist social efforts to reduce disability to an impairment, and instead focus on disability as a way of life, with exclusion caused by social attitudes that lead to stigma, prejudice, and social isolation. When disability is only understood as a medical problem, it is too easy to write off a significant number of San Franciscans as incapable and hopeless; after all, everything from Hollywood representations of disability to our choice of words ("blind to the possibilities," something "falling on deaf ears," and something bad being "lame/crazy/retarded") confirm that disability is often considered inferior. Yet a deeper analysis reveals the opposite: people with disabilities are capable of being our greatest innovators and problem-solvers, if we remove the barriers that prevent people from reaching their full potential.

Nearly every city resident is touched by disability, which can happen to anyone at any time due to genes, disease, or accident.

Disability can happen to anyone at any time due to genes, disease, or accident; this becomes more and more likely as we age. Because nearly every city resident is touched either directly or indirectly by disability – whether they are one of the ten percent of people in San Francisco who live with a disability themselves, or they are a friend, family member, or colleague of a disabled person – supporting San Franciscans with disabilities leads to benefits for the city as a whole.¹

By launching the first municipally funded disability community cultural center, the city will go beyond service provision to meet not just disabled San Franciscans' basic needs, but also their needs for culture, to feel valued, and to connect with others who share their experiences. San Francisco will show a commitment to replacing tired stereotypes of disability by fostering bold and exciting ideas that celebrate what disabled people bring to the table, all while making sure, of course, that people with disabilities have designed that table. The Center will also enhance the city's reputation as a trailblazer and champion of those pushed to the margins, especially when people with disabilities nationwide continually find themselves under attack.

^{1.} American Community Survey (2016), 5-Year Estimates.

METHODOLOGY

The Dignity Fund, which was established through a charter amendment passed by San Francisco voters as Proposition I in 2016, calls for allocating a certain percentage of the City's General Fund to improve the lives of adults with disabilities and seniors. As manager of the Dignity Fund, DAAS contracted with the Paul K. Longmore Institute on Disability to assess the need for a community cultural center dedicated to people with disabilities who live and work in San Francisco, and to determine what this population would like to see in such a center.

The Longmore Institute's eleven-month development project included an in-depth analysis of scholarly literature, resources, and models currently available, existing San Francisco community and cultural centers, and external trends; in-depth surveys and focus groups among adults with disabilities and leaders from government, nonprofit, community and advocacy organizations; and collaborative planning with a core leadership committee.

Method	Timeframe	Activities
Formation of Leadership Committee	Jun – Aug 2018	Convened leaders from disability service and advocacy organizations to design and oversee the planning process.
Background Research	Jun – Sept 2018	Visited local cultural and community centers, and researched literature and statistical data to compile a thorough Cultural Landscape.
Field Research: Survey	Sept 2018 – Jan 2019	Developed a city-wide survey that asked what people with disabilities want to see in a community cultural center; translated the survey into five languages; promoted and collected surveys in the community.
Field Research: Focus Groups	Oct 2018 – Jan 2019	Conducted focus groups with disabled people who are multiply marginalized, with individual groups for transition-aged youth, veterans, people of color, LGBTQIA+, and people experiencing homelessness.
Planning Activities	Oct 2018 – Apr 2019	Developed elements for DAAS to incorporate in the RFP for the next phase of the process, including values, vision, mission, goals, mandatory and preferred inclusions.

The Project Team

This project was managed by senior Longmore Institute staff and an independent consultant:

Catherine J. Kudlick, Director, Paul K. Longmore Institute on Disability Emily Smith Beitiks, Associate Director, Paul K. Longmore Institute on Disability Christine Poremski Rodrigues, Consultant, R&P Associates

Leadership Committee

To ensure that the design of the new center incorporates the needs and desires of the disabled people who are often the least visible, all project activities were overseen by a committee comprised of nine diverse leaders in the disability justice field, all of whom are people with disabilities. The Leadership Committee met for two hours each month from August 2018 to April 2019, in addition to an all-day retreat for strategic planning once the data was available. The committee members included:

- Nicole Bohn, Director, SF Mayor's Office on Disability
- Marti Goddard, Director of Access Services, San Francisco Public Library
- Fiona Hinze, Systems Change Coordinator/Community Organizer, Independent Living Resource Center, San Francisco
- Jessica Lehman, Executive Director, Senior & Disability Action
- Lisamaria Martinez, Director of Community Services, LightHouse for the Blind
- Orkid Sassouni, Employee at San Francisco Public Library, Deaf Services
- Tiffany Yu, CEO and Founder, Diversability
- Bruce Wolfe, Chief Information Officer, Alcohol Justice/SF Community Hand Trust/ Haight Ashbury Neighborhood Council
- Alice Wong, Founder and Director, Disability Visibility Project

Background & Field Research

Cultural Landscape Research – In the first stage, the Project Team visited local cultural and community centers and conducted an in-depth analysis of scholarly literature, resources, and models currently available, and the external trends that will affect the operations of the new Center. This research guided the development of the survey and focus group/leadership interview questions, as we explored the

possibilities of what the disability community cultural center might offer based on existing models.

Survey Research – A city-wide online survey was conducted to discover what people with disabilities, their caregivers, families, and allies want to see in a new community cultural center. In addition to asking what the Center should accomplish and what specific activities and services they would like to see, the survey also collected demographic data to ensure that respondents were representative of San Francisco's population.

To promote participation in the survey by people with disabilities – especially among individuals with intersecting identities and those not yet connected to city services – the Project Team promoted the survey through postcards, flyers, emails, blog posts, Facebook ads, and coordination with organizations and disability leaders throughout San Francisco. Copies of the survey were distributed in San Francisco's six most common languages: English, Cantonese, Spanish, Tagalog, Vietnamese, and Russian. The team also provided gift cards and collected survey responses in person at several locations to boost response among hard-to-reach people experiencing homelessness, veterans, and Asian American disabled populations. The survey was open from November 19, 2018 until January 15, 2019 and received 655 responses.

Throughout the process we worked hard to obtain results that would reflect as closely as possible San Francisco's population of disabled people. Aware that by their very nature all surveys produce inherent biases, we strove to correct for this as best we could in how we created, designed, distributed, and publicized it. Name and contact information were only solicited in an optional section at the end, which invited the participant to share if they wished to stay informed.

Focus Group Research – To complement the survey results, we convened five focus groups (sixty total participants) comprised of disabled people further marginalized by intersecting identities: transition-aged youth aged 18-24 (TAY), people experiencing homelessness, veterans, people of color (POC), and people who identify as lesbian, gay, bisexual, transgender, queer, intersex, and/or asexual (LGBTQIA+). Participants, who received \$100 gift cards, were recruited through flyers and e-blasts sent to community partners, through the Longmore Institute and leadership committee members' networks, and through in-person outreach at the SF Public Library (homeless recruitment) and the VA Hospital (veterans recruitment). In addition to asking about the unique problems they face, focus group participants were asked to describe what a community cultural center should accomplish, what specific activities and services they would like to see offered, how people with disabilities can be involved in center operations and accountability.

Disability Leader Interviews – Catherine Kudlick conducted in-depth telephone interviews with leaders of local disability service organizations, including: Access to City Employment (ACE) Program (City of San Francisco); Alliance on Mental Illness, San Francisco; The Arc of San Francisco; Coalition on Homelessness; Community Living Policy Center; Disability Program and Resource Center, San Francisco State University; Golden Gate Regional Center; Independent Living Resource Center, San Francisco; LightHouse for the Blind and Visually Impaired; Homebridge; People with Disabilities Foundation; Pomeroy Recreation and Rehabilitation Center; Student Disability Services, University of San Francisco; and Support for Families of Children with Disabilities. Members from our Leadership Committee ensured feedback from Senior Disability Action, Disability Visibility Project, the Mayor's Office on Disability, Diversability, and Access Services at San Francisco Public Library.

Leaders were asked to describe the biggest problems faced by people with disabilities in San Francisco, what they felt the goals and focus of the Center should be, as well as what concerns the team should watch for, based on the ongoing struggles they encounter at their organizations.

Detailed Cultural Landscape & Research Reports may be obtained from the **DAAS** website.

The Planning Process

Because there has never been a municipally funded community cultural center for people with disabilities, the Project Team and Leadership Committee started with a blank slate. For initial inspiration, we turned to the city's existing cultural centers. But more importantly, and in the spirit of "nothing about us without us," the rallying cry of disability activists who often have decisions imposed on them by outside "experts," we set out to discover what the people with disabilities who live or work in San Francisco themselves want a center like this to be. Our charge was not to determine a location or building specifications, or to identify the specific services and activities this new Center will offer; those decisions will be made by an organization to be selected through a competitive bidding process managed by DAAS after the completion of our contract.

After collecting information from as broad and representative a sample of disabled San Francisco residents as possible and incorporating ongoing feedback from our Leadership Committee, we distilled what we heard into a set of clear guidelines that can be used by DAAS to develop a request for proposal (RFP) document. This RFP process will be used to select the organization(s) that will ultimately design and operate the new Center.



NEEDS OF PEOPLE WITH DISABILITIES IN SAN FRANCISCO

Like those who live across the U.S., the nearly 74,000 adults with disabilities who live in San Francisco struggle with access to employment and housing, and frequent discrimination experienced through both physical and attitudinal barriers.²

Demographic Profile of Adults with Disabilities in San Francisco

An estimated 11.8% of all San Francisco residents aged 18 or older (87,073 individuals) have a disability³, with cognitive and walking difficulties being the most frequently reported:

- 55% walking difficulty
- 46% independent living difficulty
- 40% cognitive difficulty
- 26% hearing difficulty
- 25% self-care difficulty
- 20% vision difficulty



^{2.} *American Community Survey* (2016), 5-Year Estimates, total civilian non-institutionalized population aged 18 years or older in San Francisco.

^{3.} San Francisco Senior and Disability Population Demographics by Supervisorial District, San Francisco Human Services Agency – Planning Unit.

Since most disabilities are acquired through accident or illness, rates increase with age. In San Francisco, younger adults aged 18-64 are three times more likely to report a disability than children under the age of 18; and older adults aged 65+ are five times more likely to report a disability than those aged 18-64.

Disability rates also vary by race/ethnicity, with people of color being more likely to have a disability, and African Americans in particular being more than twice as likely as residents of other ethnicities to experience disability (African Americans make up 5.4% of all San Francisco residents and 14.7% of all San Francisco residents with disabilities.)⁴

An estimated one quarter (26%) of adults 18 or older with disabilities in San Francisco live below the poverty level.⁵

Barriers to Access

Nearly three decades have passed since the signing of the Americans with Disabilities Act, and yet many San Franciscans with disabilities still face unlawful discrimination in their daily lives. This plays out in everything from physical access to microagressions to outright discrimination. And individuals commonly experience several roadblocks to participation – and often face several at once. Studies have shown that people who experience such situations are more likely to experience decreased mental and physical health and well-being.⁶

Stereotypes, stigma, prejudice and discrimination are the most basic barriers to access experienced by people with disabilities, and contribute to all other barriers.

^{4.} American Community Survey (2016), 5-Year Estimates.

^{5.} American Community Survey (2016), 5-Year Estimates.

^{6.} Derald Wing Sue, Christina M. Capodilupo, Gina C. Torino, Jennifer M. Bucceri, Aisha M. B. Holder, Kevin L. Nadal, and Marta Esquilin, "Racial Microaggressions in Everyday Life: Implications for Clinical Practice," *American Psychologist*, 62:4 (May/June 2007) 271–86.

Attitudinal barriers came up repeatedly in background research and focus group conversations. The 2016 Dignity Fund Needs Assessment found that San Francisco residents – especially younger adults – display limited awareness of the challenges facing adults with disabilities, which compounds existing barriers to service engagement.⁷ This finding was confirmed by focus group participants, who were all disabled and members of other marginalized groups. Many spoke passionately about how their intersecting identities (being both a person with a disability and also a person of color, LGBTQIA+ person, a person experiencing homelessness, a veteran, or a young person transitioning to adulthood) led to persistent discrimination, stigma, prejudice, and/or invisibility.

Focus group participants also described the frequency with which they encounter:

- physical barriers presented by inaccessible spaces that have no ramps or elevators, presence of scents and other chemicals
- communication barriers, such as not having American Sign Language (ASL) interpretation
- policy barriers that result when laws and regulations that require that programs and activities be accessible are not upheld or actively limit disabled people's rights
- transportation barriers, such as public transportation that is inconvenient or inaccessible and which decreases disabled people's ability to be independent and interact socially
- social barriers that result from disabled people having a perceived lower position in the social hierarchy, which affects their ability to find housing, jobs, and education, and which has a direct impact on their health and well-being

Places For Younger Adults With Disabilities

The fact that Aging and Disability Resource Centers are open to disabled adults of all ages is offset by their being housed in senior-focused agencies. Indeed, the Dignity Fund Needs Assessment found that many younger adults with disabilities in San Francisco perceive that services and programs are "more fluid and easier to navigate for older adults (seniors) than for younger adults with disabilities...who may see resources like Aging & Disability Resource Centers as only for older adults." This

^{7.} Dignity Fund Community Needs Assessment, developed for the San Francisco Department of Aging and Adult Services by Research Development Associates, March 2018.



perception was even more pronounced among TAY, who said that these centers were less likely to provide services that were tailored for them, including support for seeking full-time employment.⁸

While most of the services offered through Aging & Disability Resource Centers are open to disabled adults of all ages, the fact that they are often housed in seniorfocused agencies leads to a perception among younger adults that these services are intended for seniors only.

^{8.} American Community Survey (2016), 5-Year Estimates.

THE IMPORTANCE OF DISABILITY CULTURE

While every phase of researching this project revealed a strong, ongoing need for basic services, many survey participants and people we interviewed advocated for something more.

Research respondents saw the **new disability community cultural center** as key for breaking out of the traditional service provider model because it promised a supportive place where issues such as prejudice and low self-esteem could be addressed and even countered.



Central to these dreams is disability culture, an idea that many people – including those within disability communities – have never paused to consider even though it is part and parcel of the disability rights movement. Until the 1960s and 1970s, "the handicapped" were viewed predominantly as patients, as individual victims of a particular misfortune. Known as the "medical" or "pathology" model, these limiting beliefs continue to dominate mainstream representations in everything from movie portrayals to news stories. With the birth of a disability rights movement in the 1960s (one modeled on the black civil rights movement in the United States) a growing number of disabled people began to see themselves more as a social or ethnic minority than as victims of biology. While many still seek out and benefit from medical interventions, they argue that being assured of basic rights and opportunities is equally, and oftentimes even more, important. Known as the "minority" or "social model," this approach has led to exploring ideas of collective identity and powerful community where many found common cause as they struggled against years of shame and prejudice.

Disability scholar and activist Steve Brown explains, "People with disabilities have forged a group identity. We share a common history of oppression and a common bond of resilience. We generate art, music, literature, and other expressions of our lives, our culture, infused from our experience of disability. Most importantly, we are proud of ourselves as people with disabilities. We claim our disabilities with pride as part of our identity. We are who we are: we are people with disabilities."⁹

"We share a common history of oppression and a common bond of resilience. We generate art, music, literature, and other expressions of our lives, our culture, infused from our experience of disability... we claim our disabilities with pride as part of our identity." – Steve Brown

As it has come into its own over the past two decades, disability culture has increasingly challenged long-cherished notions of independence and selfdetermination as being rooted in a system that privileges the values of white,

^{9.} Stephen E. Brown, "Disability Culture and the ADA," *Disability Studies Quarterly* 35:3 (2015) Accessed on 17 June 2018 at <<u>http://dsq-sds.org/article/view/4936/4062.</u>> <<u>http://www.instituteondisabilityculture.org/what-we-mean-by-disability-culture.html.</u>>

nondisabled, heterosexual modes of existence. It seeks to reflect the reality of disabled people's lives by showing how society and basic needs must be understood in terms of interdependence and cooperation rather than competition and individual striving. True to the activist rallying cry of "nothing about us without us," disability culture is generated from within disabled communities rather than being imposed by outsiders. It prioritizes bringing more people into more conversations while creating opportunities for individuals to connect.

"The **brilliance of disability comes from this innovation and commitment to not leaving each other behind.** It includes the power of a march moving as slow as the slowest members, who are at the front All while building cultures where we don't shame each other for being sick or having needs."¹⁰

Such ideas that feed into disability culture have been expanding at universities across the country and around the world in the field of Disability Studies. Over the past thirty years, scholars in a variety of disciplines from the social sciences and humanities have explored a wide range of topics: government policies, family relationships, economic disparities, histories of forced sterilization and eugenics, depictions in literature and media, intersections with other identities, challenges to the status quo. This has helped spawn a growing number of campus-run disability centers (different from offices that offer disability accommodations) much like those for other identity groups.

Meanwhile, Bay Area-based disability arts programs led by people with disabilities, such as AXIS Dance Company, Superfest Disability Film Festival, and Sins Invalid have blazed a trail for community gatherings and innovation. Such initiatives have enhanced and benefitted from overlapping movements within communities of color and conversations among LGBTQIA+ people to promote what is increasingly

^{10.} Leah Piepzna-Samarasinha, "To Survive the Trumpocalypse, We Need Wild Disability Justice Dreams." *Truthout*, (May 20, 2018), < <u>https://truthout.org/articles/to-survive-the-trumpoca-lypse-we-need-wild-disability-justice-dreams/</u>> Accessed May 23 2018.

understood to be disability culture. These arts groups are positioned to provide cultural programming by and for people with disabilities from the moment the Center opens and enable San Francisco's DCCC to leap into the Bay Area's vibrant cultural scene. Buttressed by both scholarly research and community credibility, the Center is well positioned to deliver on the promise of stretching thinking about disability and disabled people among all San Francisco residents.

When viewed through the popular lens of Maslow's "Hierarchy of Needs," it is tempting to think that culture could be a low priority, provided as "the cherry on the top" only after all other basic needs are met. In this view, the pursuit of belonging and friendships, self-esteem, and self-fulfillment can only come <u>after</u> a person's basic needs for food, water, warmth and rest, have been met. But because Maslow's theory does not address the importance of social connection, it misses the role that culture plays in ensuring that basic needs for food and safety are met. As psychologist Pamela Rutledge points out in her critique of Maslow's reasoning, "It was not possible to defeat a Woolly Mammoth, build a secure structure, or care for children while hunting without a team effort.... Belongingness is the driving force of human behavior, not a third tier activity."¹¹

Promoting culture can be one of the most powerful ways to address the many barriers caused by discrimination toward people with disabilities in San Francisco.

We know, for example, that social discrimination can lower an individual's selfesteem, which in turn hurts their ability to make healthy, constructive, and adaptive life decisions and, in many cases also leads to anxiety, depression, and other mental health issues. We also know that communities that face social discrimination experience greater barriers to jobs, housing, education, and healthcare services, both on an individual and institutional level. Simply put, promoting culture can be one of the most powerful ways to address the ongoing discrimination and low self-esteem that keep San Franciscans with disabilities from meeting their basic needs and participating fully in society.

^{11.} Pamela B. Rutledge, "Social Networks: What Maslow Misses," *Psychology Today*, (2011), < <u>https://www.psychologytoday.com/us/blog/positively-media/201111/social-networks-what-maslow-misses-0</u>.> Accessed March 15 2019.

Two concrete examples of how taking a cultural approach can remove barriers when working with marginalized people come from the education sector. In 2016, Stanford researchers found that when they introduced a 9th-grade ethnic studies curriculum at several San Francisco high schools, minority students who were assigned to the class saw a significant increase in attendance, grade point average, and credits earned. In another study in 2009, seven urban teachers found that following a culturally relevant curriculum helped prepare students to effect change in their communities and the broader society.¹²

Educators have learned that knowledge of one's own culture has a direct impact on academic achievement, and that integrating the experience of students from marginalized groups – especially those who are struggling at school – encourages them to participate to the fullest extent in their own education. Integrating culture into educational curricula can also have a systemic benefit, as marginalized people who know their own history and develop a sociopolitical consciousness are better equipped to identify injustices and fight for positive changes for their communities and society as a whole.

If we only provide services to help people with disabilities get their basic needs met, we remain in a cycle of service dependency. Culture provides an opportunity to break the cycle. As the disability rights movement has shown, when disabled people have a sense of their collective identity and culture, they feel more empowered to fight for social change and resist discrimination, and often when people with disabilities bring change, it benefits us all. Consider curb cuts, which benefit not only wheelchair riders, but also delivery people, tourists with rolling suitcases, and parents with strollers. Additionally, disability culture offers other positive impacts disabled people have had on our world, from technology to arts to creative workarounds. When teachers, employers, and potential romantic partners understand people with disabilities as innovators who offer a unique perspective and new ways of being in the world as opposed to helpless, incompetent victims of tragedy, invariably there will be less strain on basic services like employment and housing support.

^{12.} Jennifer Esposito and Ayanna N. Swain, "Pathways to Social Justice: Urban Teachers' Uses of Culturally Relevant Pedagogy as a Conduit for Teaching Social Justice." *Perspectives on Urban Education*, (Spring 2009) 6:1, 38–48, <<u>https://files.eric.ed.gov/fulltext/EJ838745.pdf</u>> Thomas Dee and Emily Penner, "The Causal Effects of Cultural Relevance: Evidence from an Ethnic Studies Curriculum," *CEPA Working Paper No.16-01*, (2016), Retrieved from Stanford Center for Education Policy Analysis, <<u>http://cepa.stanford.edu/wp16-01></u>

RESEARCH FINDINGS

Nine months of extensive research among people with disabilities and their caregivers, families, and allies revealed overwhelming support for a San Francisco DCCC. The fact that more than half of our survey participants asked to be added to a mailing list for updates on its progress, and more than a quarter of respondents want to volunteer once it is open or serve on an advisory board further underscores the growing excitement. The Longmore Institute has even been receiving calls weekly from community members asking for the Center's hours of operation.

Focus group conversations and interviews with disability leaders yielded additional qualitative data that bolstered the survey data's conclusions. Participants shared their own stories in ways that the survey did not allow for, and these narratives underscored the value the Center would provide to individuals and groups who could be making valuable contributions with access to a supportive place that will combat stigma and foster a sense of community and pride.



Direction The DCCC Should Take

The survey's broad opening question invited respondents to assess how highly they prioritize a list of possible directions for the DCCC that included advocacy, networking, learning about services, etc. Interestingly, responses yielded no clear direction for the Center because everyone was generally favorable to all of the priority options presented, with each one receiving an average score of between medium and high priority. In-depth conversations with disability organization leaders revealed similar findings. While the leaders interviewed brought up a shared concern that the new Center not reproduce existing services or programs, they expressed across the board enthusiasm for all areas. Such agreement strongly suggests not just a great desire for such a Center but also that it will have the ability to address many pent-up needs.

Center Goals

Survey respondents were asked to choose and rank their top three out of six proposed goals for what impact the Center should have. Three clearly rose to the top among the people with disabilities who live and work in San Francisco:

- Bringing together diverse people with disabilities this option received the most votes for the #1 goal across nearly all demographic groups.
- **Promoting social justice for people with disabilities** this option received the most votes for #2 goal, and many votes for #1 as well.
- Celebrating disability arts and culture this option received the most votes for #3 goal.

While the other goal options received fewer votes, they still showed strong support, and are complementary to those above.

- Educating the general public while this option didn't rise to be a top goal, it still received a high number of votes overall.
- Elevating the status of disabled people this option received consistent support overall, and there may be an opportunity to integrate this within the goal of promoting social justice.
- **Building disability pride** in our focus groups we discovered that many people with disabilities had never heard of the concept of "disability pride" and were puzzled as to what it might mean to them.

Center Activities and Services

Overall, respondents indicated interest in most of the activities and services suggested, with all but two receiving a total weighted average score between "somewhat" and "very interested." The bar chart below displays the weighted average score for each option, based on a score of 2 for "somewhat interested" and 3 for "very interested."



Exploring a little further, three options received the most "very interested" ratings and the highest weighted average scores (again, with a score of 2 for "somewhat interested" and 3 for "very interested"):

- **Disability education** (2.55) disability studies lectures, disability awareness month and ADA celebrations, disability history, heritage and preservation activities, etc.
- Arts and cultural performances by/for disabled people (2.54) theater, dance, comedy, film, etc.
- Advocacy (2.53) education, networking, and training on how to advocate for disability rights)

Most other options received good ratings, with a weighted average score between "somewhat" and "very interested."

- Legal (2.47) advice, counseling, documents, representation
- Maker Spaces (2.47) artist/craft spaces and workshops
- **Transportation** (2.46) information and discounted passes
- Art Galleries (2.45) exhibitions of art by disabled people
- **Benefits Training** (2.44) how to access housing support and other public benefits and services
- Identity Group Meet-Ups (2.41) (LGBTQIA+, people of color, disability types, caregivers, parents, etc.)
- Benefits Assistance (2.38) information and enrollment
- Café & Work Space (2.37)
- Entertainment (2.36) games, book clubs, film screenings, etc.
- **Computer & Technology** (2.34) public computer lab, assistive technology trainings, tech fairs, new product testing and demos, development of new and "beta" products, etc.
- Music & Dance (2.32) classes and clubs
- Health (2.28) nutrition, fitness and wellness classes
- **Employment** (2.23) coaching, workshops, strategies for how to discuss disability status
- Housing (2.21) opportunities, applications, rental assistance
- Food & Nutrition (2.11) subsidized lunches, food pantry, nutritional counseling
- Sexual Health (2.05) education, skills, safety, parenting)
- Career Networking (2.02)

Only two options received a weighted score below "somewhat interested."

- **Private Event Space Rental** (1.87) parties, weddings, funerals, community events, etc.
- **Sports** (1.63) club teams, adaptive sports

While the ratings did not identify clear "winners" among the various options for activities and services, they did show broad interest among San Franciscans with disabilities in most of the proposed activities that could be offered through the DCCC.

DISABILITY COMMUNITY CULTURAL CENTER PLANNING

Addressing The Dignity Fund Needs Assessment Recommendations

The 2018 Dignity Fund Community Needs Assessment described several recommendations for how DAAS could address the unmet service needs of adults with disabilities in San Francisco, including:

- Expanding existing services to incorporate multicultural, intergenerational, and other opportunities for community-building and social interactions.
- Expanding outreach efforts and culturally appropriate services, with special attention to specific strategies and services to engage younger adults with disabilities.
- Examining how social cohesion/sense of community can be leveraged to engage underrepresented populations.
- Maximizing collaborative efforts across agencies, departments, and providers.
- Identifying opportunities to collaborate with City departments to serve adults with disabilities experiencing homelessness.
- Expanding services that use integrated and collaborative approaches, including intergenerational and multicultural collaborative programs.
- Supporting collaboration between community-based organizations.¹³

Our research and planning process has identified a number of ways we can address community concerns as well as the recommendations offered in the extensive Dignity Fund Needs Assessment.

Guidance for Developing the Center

The following DCCC guidelines were developed and approved by the project's Leadership Committee, with the support of the Project Team. They are based on the results of the background and field research along with the personal experience and expertise of the disabled leaders involved. We have designed them to help DAAS develop a request for proposal (RFP) document that requires all applicants to describe how their proposals will address the needs and desires of the people with disabilities as outlined in our research.

^{13.} Dignity Fund Community Needs Assessment, developed for the San Francisco Department of Aging and Adult Services by Research Development Associates, March 2018.

Values

Values are the enduring beliefs that create a shared code for how a group operates, behaves, and makes decisions. While a group's mission or goals may evolve over time, values are unchanging and constant, and serve as anchor point as the group responds to a changing world.

DCCC Values: The San Francisco Disability Community Cultural Center will be guided and informed by our belief and commitments to the following values:

Community – We believe in building connections within and among disability communities and with the general public because no community should exist in isolation from others.

Leadership – In the spirit of "Nothing about us, without us," we hold the leadership, expertise, and wisdom of people with disabilities at the core of everything the Center does.

Collective Access – We welcome the insights and participation of people with all types of disabilities, and embrace interdependence in the pursuit of access. We respect and honor diverse experiences and share responsibility for creating access for each other.

Social Justice – We strive to create a community and world in which all people with and without disabilities are treated with dignity and respect. We recognize that justice for people with disabilities is tied to the liberation of all people.

Intersectionality – We acknowledge and value people with disabilities who live at the intersections of multiple axes of oppression. We recognize that there is no singular idea of disability. We bring our full selves, with all of our identities and perspectives, everywhere we go. Joy – Pleasure, laughter, creativity, and innovation are central aspects of disability culture and our lived experience.

Problem & Purpose

Before any group can design the new DCCC, it is critical to first identify why the Center is needed.

The Problem the DCCC Intends to Solve: People with disabilities in San Francisco experience discrimination, social isolation, lack of access, and other forms of ableism, without a place of our own where we can restore ourselves, feel safe, and connect with each other. People with and without disabilities do not recognize disability identity and the disability community as deserving of celebration and honor. The Purpose of the DCCC: To provide a dedicated place where people with disabilities can gather, gain access to information and resources, and develop our culture while feeling welcome and valued.

Mission

If the problem and purpose explain why there is a need for the DCCC, then the mission describes how this will occur. The mission statement describes the path that will be taken to reach the desired destination, the unique approach that an organization will take to solving the identified problem. The mission is the strategy for how an organization will deliver its desired results. Having a clear mission allows groups to stay focused on what is most important and eliminate distractions.

DCCC Mission: By providing educational, artistic, and social networking opportunities, the San Francisco Disability Community Cultural Center brings diverse people with disabilities together to access resources, advance social justice, and foster disability culture, community, and pride.

Vision

A vision statement is a sensory description of the ideal future that results once the mission has been achieved. If purpose is the why and mission is the how, then vision describes what the impact will look like. Having a vision statement is critical because it is used to inspire and motivate both the stakeholders who do the work and those who contribute resources to support the work.

DCCC Vision: We envision a city with a strong sense of disability culture and identity, where the people with disabilities who live, work, and visit here actively engage in the services and supports available to them, fully participate in civic life, and feel valued and proud of who they are.

Goals

Goals are specific targets or destinations to be reached as a result of the activities included in a plan that collectively lead to the achievement of an organization's mission. Because there are so many potential directions the DCCC could take, clearly articulated goals offer an essential guide for Center operations and ensure that resources are being directed to the most important and relevant activities. In our research, we asked people with disabilities to tell us what the new DCCC should achieve. While we received a wide variety of responses, they can be distilled into the following overarching goals:

DCCC Goals: The themes that will guide center operations include:

- Creating a space for diverse people with disabilities to come together.
- Advancing social and disability justice.
- Celebrating disability culture, community, and pride.
- Providing information about and access to disability programs and services.

"I've never really felt validation for who I am. Even from my family, I've been told, 'I have this and it's a handicap and I don't have a sense of pride for anything.' I don't know what disability pride is. I want to feel like I don't constantly have this burden."– Focus Group Participant (TAY, POC)

Activities

While the purpose of this project was not to design the specific programs and services to be offered at the new DCCC, we did ask about a wide variety of possibilities. Our aim was to gage general interest and to see whether some activities appealed to different demographic groups. By cross-referencing the individual activity ratings from the survey, focus groups, and interviews with the goals that were collectively identified as being most important to people with disabilities, we determined the following:

The primary focus of all DCCC programs and services must be on directly serving people with disabilities who live and/or work in San Francisco. In accordance with the value of holding the leadership, expertise, and wisdom of disabled people at the core of everything the Center does, DCCC programming and activities should:

- Provide centralized information, resources, and referrals, and selected direct services in a highly visible cultural space that also draws individuals not already connected to services.
- Offer self-advocacy training in how to obtain services and resources as well as in how to be activists and effect systemic social change.

- Provide opportunities for creative expression, socializing, and developing personal relationships.
- Provide a safe and accessible place in San Francisco where people with disabilities feel connected and feel they belong.
- Offer leadership opportunities through employment, volunteering, and/or serving on an advisory board.
- Provide education about disability history, other disability types, and the experiences of people with disabilities with intersecting identities in order to develop sociopolitical consciousness and understanding of diverse sub-communities.
- Foster a sense of disability culture, identity, community, and pride.

Recognizing that disabled people are supported by a network of non-disabled family members, caregivers, service providers, allies, and other disability sub-communities, the DCCC should also include activities that build connections and improve coordination between and among disability communities, providers, and allies.

And since one of the priorities of the Center is to reduce discrimination against people with disabilities and to integrate them more fully into society, the DCCC should also seek to improve the social standing of people with disabilities among the general public. Activities could include educating non-disabled visitors about the disability experience, culture, and history; how to honor access needs; and how to support public policies and programs that benefit people with disabilities and protect their civil rights.

To further ensure that people with disabilities are fully integrated into San Francisco society, the DCCC can also host meetings of nondisabled groups, provided that these events are accessible to all who are interested. Such partnering not only offers an educational function by teaching potential visitors about access and inclusion, but also facilitates interactions between disabled and nondisabled people, another desire expressed through our focus groups and leader conversations.

Last but not least, there was a strong consensus that every effort be made to hire and retain staff who are people with disabilities. Indeed, staffing repeatedly came up as a key component in making the Center feel both welcoming and safe.

VISIONS OF THE NEW CENTER

It seems fitting to end this report, as we did each focus group and one-to-one leadership conversation, by sharing what disabled participants imagined at the opening party for the new DCCC.

"Somebody's greeting me, saying, 'Hey, welcome to our new home. This is our home.'"

"And what's most important that you'll see once it opens? News vans."

"There's a ribbon-cutting, there's a band. It's a big day. This is a good day!"

"Everyone is scent-free."

"When I walk in on opening day, whether it's myself as a disabled individual looking for community or myself as a mom looking for resources for my disabled son or an educator that wants space or community organizer, I will walk in and be like, 'I belong in this space.' "

"I think people would totally have a sense of excitement... A big celebration."

"[I see] all of us here. Different disabilities, different cultures."

"You get good vibes [when you walk in.]"

"Real great conversations happening in room. People really, really happy to be with each other, like a family."

"I see openness and glass windows...we're going to let people see us."

During one of our monthly meetings, Leadership Committee members were asked to imagine a newspaper headline that might appear when the center opens. Responses included:

"San Francisco Strikes Again!"

"History Made: SF Blazes The Trail for Adults with Disabilities"

"History Made, Thousands of People with Disabilities Swarm New Cultural Center"

"SF Disability Community Finally Acknowledged"

"Ribbon-Cutting for First Disability Cultural Center in the Nation"

"LA, NY, and DC All Jealous of SF's New Disability Cultural Center"

"Cultural Center Celebrates Disability Community and Innovation"

"'A Place For Us' - People With Disabilities Come to Celebrate"