Perceptions of Disability, Identity, Agency, Goal Attainment, and Young Adult Disability Programs

Rachel Elizabeth Kallem Whitman

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PERCEPTIONS OF DISABILITY, IDENTITY, AGENCY, GOAL ATTAINMENT, AND YOUNG ADULT DISABILITY PROGRAMS

A Dissertation
Submitted to the School of Education

Duquesne University

In partial fulfillment of the requirements for the degree of Doctor of Education

By
Rachel Kallem Whitman

May 2017
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Rachel Kallem Whitman

2017
PERCEPTIONS OF DISABILITY, IDENTITY, AGENCY, GOAL ATTAINMENT, AND YOUNG ADULT DISABILITY PROGRAMS
ABSTRACT

PERCEPTIONS OF DISABILITY, IDENTITY, AGENCY, GOAL ATTAINMENT, AND YOUNG ADULT DISABILITY PROGRAMS

By

Rachel Kallem Whitman

May 2017

Dissertation supervised by Dr. Rick McCown

Youth with disability are oppressed and marginalized by a dominant cultural narrative called ableism (Adams, Reiss, and Serlin, 2015; Campbell, 2015 as cited in Adams et al., 2015). Challenging ableism is a matter of social justice. Without serious attitudinal shifts and the removal of systemic barriers, our youth with disabilities will continue to experience negative outcomes and underdeveloped agency. This study was conducted to provide a more detailed look into how adults with disabilities, who participated in disability advocacy programs as youth, perceive their past involvement with such programs in relation to defining their disability, identity, and capacity for agency. In addition, the study sought to assess the relevance of disability-positive environments based on participants’ perceptions. The study’s primary research question was: How and to what extent do youth with disabilities perceive disability advocacy
programs in Pittsburgh as disability-positive environments? The supplemental research question was: How do young professionals with disabilities perceive and describe living with a disability, developing an identity, and maturing as an agent in the context of past participation in a disability advocacy program?

Ten participants were included in the study. Participants were young professionals with disabilities recruited through the researcher’s advocacy network. This study collected qualitative data through semi-structured, in-person interviews. Data were organized and analyzed using Template Analysis; contextualized through the parameters of social cognitive theory, the youth-adult partnership model, and principles of disability-positive environments. The following major themes emerged from the interview data: (1) their seminal experiences with disability as children and as young adults; (2) how they cultivated, defined, and internalized their disability-identity; and (3) how their sense of purpose and achievements provided context for future plans.

The concept of disability-positivity, social cognitive theory, and the history of youth-adult partnerships were used as frames to organize the findings into a model called, the Path of Advancement for Development of Positive Disability-Identities model. This model captures the four stages the interviewees experienced during their transition from adolescence to young adulthood. The stages cover avoidance of disability, self-defining epiphanic experiences, established individualized goals and roles, and the accumulation of these experiences, perceptions, accomplishments, and action plans are represented by stage four, the actualization of positive disability-identities.

This study found that the development of agency was not situated in any particular advocacy program. Rather, the interviewees’ perceptions of agency and their
experiences as individuals with disabilities living in an ableist society were woven into an
organized narrative that shaped an understanding of disability, identity, and forged a
driving sense of purpose that translated into achieving meaningful goals. The dissertation
ends with my agenda as an educational leader: to create a cross-disability advocacy
collective that will empower, partner, and amplify strong, new disability narratives with
the objective of replacing ableism with agency.
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Perceptions of Disability, Identity, Agency, Goal Attainment, and Young Adult Disability Programs

Chapter 1

Framing Disability and Disability-Positive Environments

In today’s world “disability” connotes significantly more than a simple diagnosis. The ramifications of being labeled “disabled” are far reaching and impact not just the individual but also families, communities, institutions, and systems. The construct of “disability” carries with it serious implications regarding ability, personhood, and autonomy and is often considered a predictor for quality of life. Living with a disability is synonymous with being “less than” and this subsequently draws severe distinctions between neurotypical, able-bodied individuals and their “inferior” peers with disabilities. These prejudicial attitudes and discriminatory actions are byproducts of disability oppression, which is known as ableism in the field of disability studies (Adams et al., 2015; Campbell, 2015 as cited in Adams et al., 2015). Ableism has a firm grasp on how we culturally conceive living with a disability and expressions of ableism are prevalent in a multitude of societal service systems. In sum, ableism is a term that describes the “all-encompassing system of discrimination of people living with disabilities,” which functions on individual, institutional, and cultural levels to put people who are non-disabled at an advantage (Adams, Blumenfeld, Castañeda, Hackman, Peters, and Zúñiga, 2013).

The predominant ableist models of disability are the medical model of disability and the charity model of disability (Adams et al., 2015, p. 2; Kemp, 1981). These two paradigms explain and orient disability as a sign of brokenness that needs to be fixed and
a sign of pitifulness that requires charitable contributions for survival. Both propose, promote, and perpetuate a paternalistic relationship between individuals deemed able-bodied and neurotypical and those with disabilities. This relationship, hinged on a clear power differential, frames individuals with disabilities as passive recipients of able-bodied, neurotypical services. This ableist narrative is often conveyed through the utilization of *inspiration porn* (Young, 2014). *Inspiration porn* interprets disability as a condition that necessitates low expectations, limited goals, restricted autonomy, and breeds a condescending mindset regarding the capacity and competency of individuals with disabilities.

Ultimately the medical model of disability, the charity model of disability, and *inspiration porn* draw a firm line between which bodies and minds are “normal,” and thus able, and which bodies and minds are forecast as stunted. This damaging ideological interpretation of disability results in negative outcomes for individuals with disabilities, including decreased success in education and employment, poorer healthcare status, and lower quality of life overall. As ableist models and narratives continue to frame disability as inferiority, stereotypes and prejudice continue to increase. This further reinforces stigma, discrimination, and exclusion and as individuals with disabilities internalize the message behind these practices they continue to struggle with their capacity for agency. The culminating result is a society that continues to frame and interact with disability as insufficiency as evident by the limited access, inadequate accommodations, diminished opportunities, and visible inequity experienced by individuals with disabilities. Inclusion for the disability community is noticeably and consistently deprioritized.
This work examines the paradigm of disability-positivity, heavily influenced by the social and biocultural models of disability, which aim to explore disability not as a medical diagnosis, a stereotyped status, or a lesser identity but as a way life experienced, which can be significantly improved or damaged by cultural interpretations of ability and difference. Disability-positivity incorporates core elements of the social and biocultural models of disability as it seeks to explore disability not as a limited condition in and of itself but as a condition that challenges our social, political, and economic understanding of citizenry, productivity, human rights, and equity. In essence it poses the question, if societal norms provided equitable access for people of all abilities, how would our definition of what constitutes a disability be altered. Disability-positivity does not propose that disability is unequivocally a “positive” thing but rather disability is a diagnosis and potential identifier that is not unambiguously negative. With support, opportunities, and education, individuals with disabilities can lead lives that are not limited by their disability. Rather they are enriched by their learned ability to make informed decisions and request effective accommodations that empower them to access the life they want. Disability does not have to predict negative outcomes.

However, as mentioned previously, disability is not inherently positive or intrinsically negative, but personally nuanced and complicated. Advocacy efforts that have systematically taught youth to embrace “being special” have in part contributed to negative consequences for the disability community by reinforcing low expectations. Young people who are indoctrinated with the carte blanche ideals of “disability pride” often have an unbalanced understanding of disability and face difficulty forging a personal relationship with disability. Disability is not an earned achievement and being
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proud of a detached, impersonal label can actually detract from a young person’s capability to establish and achieve meaningful goals that are worthy of pride. However a contrasting argument articulated by some individuals with disabilities, particularly the autistic community, is that their identity and their disability are so intricately interconnected that not embracing their whole self, denying pride in their disability, is equivalent to living an inauthentic life; it is synonymous with carrying a degree of shame (Autistic Self Advocacy Network, 2016). I contend that there should be an equally distributed emphasis on both the embodiment of disability pride and individualized goal setting and action that serve to shape identity and empower the individual.

Finally, this work examines our cultural narrative of leadership and its related implications. Research has found that in addition to holding low education, employment, and quality of life expectations for youth with disabilities, we also maintain low expectations for youth with disabilities becoming leaders. In order to foster leadership development amongst youth we must support their cultivation of a unique disability identity and provide opportunities through which they can utilize their individualized narrative to guide their goals, their actions, and their role in the community.

After an in-depth examination of the cultural frameworks that situate and perpetuate our dominant ableist narrative of disability in conjunction with a comprehensive review of the literature and past research, this dissertation is well positioned to address the problem of practice. I have defined an instructional model to better facilitate learning, self-reflection, and goal setting entitled "disability-positive environments." Disability-positive environments fundamentally aim to provide safe spaces where youth with disabilities can develop healthy and individualized relationships
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with identity, disability, and agency through narrative. Disability-positive environments also focus on respecting disability history, honoring disability culture, and promoting authentic disability accounts. Disability-positive environments combine integral elements from Bandura’s social cognitive theory and the youth-adult partnership model to operate as comprehensive and effectual systems. Incorporating conscientious reflection, agency, and the importance of goals from social cognitive theory and prioritizing the integration of reflection, shared vision, and joint decision making from the youth-adult partnership model enables disability-positive environments to help develop a more empowered disability culture. Additionally, disability-positive environments employ disability-positive content and disability-positive principles in order to enhance agency, access, advocacy, activism, and leadership. Disability-positive environments provide youth authentic learning opportunities so they can gain experience working in a team and practice making decisions in a safe space. By engaging diverse youth, supporting intersectionality, creating dedicated spaces for self-directed learning, and nurturing youth as they establish goals, disability-positive environments empower young people to gain relevant and meaningful generalizable skills.

Empowering young people to build a more functional relationship with disability is a matter of social justice. Individuals with disabilities will continue to struggle with a variety of life domains until we shift our ableist understanding of disability into a disability-positive framework. The social model of disability and the biocultural model of disability, which reflect the ethos of disability-positivity, seek to afford individuals with disabilities opportunities to become actualized participants in society. Disability rights are human rights. Individuals with disabilities need to be respected and acknowledged as
equal citizens and thus be granted full access and inclusion in everyday society. This means access to educational opportunities, gainful employment, sufficient health care, economic freedom, political participation, and forging social relationships in order to enhance their capacity as effective agents, advocates, activists, and leaders.

Disability advocacy in Pittsburgh, PA, has a long and rich tradition of personal empowerment and cross-system, cross-agency partnerships. Local government entities, non-profit organizations, education and medical systems, parents, and advocates have worked together to improve access and increase opportunities for the disability community via a wide continuum of initiatives and projects. The current disability advocacy infrastructure in Pittsburgh supports and serves a wide spectrum of youth with disabilities but some of these programs, recreational opportunities, and skill-building groups are lacking in regard to how they intentionally and effectively empower youth as competent and capable agents. The initial focus of my research was to learn from youth with disabilities enrolled in such disability-oriented groups how these programs influence their practice of agency and impact their understanding of disability identity. However, due to issues recruiting participants, the focus of my research shifted towards learning how young professionals with disabilities perceive disability advocacy programs they participated in in the past in relation to disability-positive environments. A follow-up area of study was exploring how these young professionals perceive and describe living with a disability, developing an identity, and maturing as an agent via reflecting on adolescent experiences and current perceptions. My work in Pittsburgh has contributed to my belief that creating disability-positive environments will target and improve the efforts of an already promising advocacy network. However, directly engaging stakeholders is
paramount in order to learn what factors they perceive to be the most valuable, impactful, and memorable when it comes to the maturation of their agentic identities; thus, semi-structured, one-on-one interviews were conducted.

In closing we must challenge how we define disability by expanding our principles, practices, and platforms in order to increase access and justly practice inclusion. Ideally this valuable research opportunity will allow me to better understand what it is like living with a disability, developing an identity, and maturing as an agent in the context of a potential disability-positive environment in Pittsburgh, PA. When youth with disabilities have a higher capacity for agency they are increasingly likely to navigate life’s many transitions successfully. Furthermore as young people with disabilities become smart goal-setters, competent problem solvers, and authentic achievers, their accomplishments challenge the low expectations of ableism. I contend that youth with disabilities who have participated in disability-positive environments are more likely to be skilled agents, advocates, activists, and leaders who can actively erode our ableist definitions of disability and ability.

A Society of Staircases

The cultural narrative of disability prevents individuals with disabilities from forming identities as agents. Young adults with disabilities must frame their understanding of disability in a predominantly neurotypical, able-bodied world. Many activists and advocates contend that experiencing “disability” is more a matter of hindered societal access and limited inclusion than a medically problematic phenomenon. We unjustly use the disability label to categorize and trivialize people who differ from the “normal” neurotypical, able-bodied individual. Our ongoing assumption is that the
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default human being is neurotypical and able-bodied unless otherwise specified. This
default human being is a member of dominant culture who looks, walks, talks, thinks, and
experiences the world in a routine, predictable way. Normalcy is the praised state of
being and the desired expectation in order to have a productive existence.

Ableism. We live in a society that disempowers those with disabilities via a cycle
of neurotypical, able-bodied privilege. This prejudicial system of beliefs that is
continuously reinforced by a cycle of disability disempowerment is collectively known as
disability oppression or ableism (Adams et al., 2013. Ableism operates on a platform that
there is an objective and desirable “normal body” and thus a clear divide between
developed humanity and underdeveloped humanity (Campbell, 2015 as cited in Adams et
al., 2015, p. 13). “Ableism denotes the ideology of a healthy body, a normal mind,
appropriate speed of thought, and acceptable expressions of emotion;” in a culture where
the human body is measured and valued based on efficiency, people with disabilities are
excluded (Campbell, 2015 as cited in Adams et al., 2015, p. 13).

Ableist models of disability. The field of disability studies explores the construct
of disability and dissects the experience of “being disabled” through social, cultural, and
political dimensions (Adams et al., 2015, p. 2). The ethos of ableism undergirds the bulk
of our dominant disability narrative through the perpetuation of the medical model and
charity model of disability. The medical model of disability is a limiting, dehumanizing,
and potentially damaging view of disability as it stipulates that the “disabled body” needs
to be “corrected” and “cured” (Adams et al., 2015, p. 2). The charity model of disability
frames the relationship between the “nondisabled” and “disabled” as a one-directional
recipient arrangement (Kemp, 1981). Individuals without disabilities donate financial
resources, volunteer hours, and often pity to “save” their passive, “disabled” counterparts, which actually disempowers, perpetuates stereotypes, and interferes with self-determination (Kemp, 1981). Scholars and practitioners in disability studies hold that ableist frameworks like the medical model of disability and the charity model of disability reinforce negative expectations for the disability community and enforce exclusion and inaccessibility.

**Disability-positive counter narratives.** In contrast, the majority of disability studies scholars utilize the social model of disability and the cultural model of disability, which directly challenge ableist models. The social model of disability maintains that societal norms and expectations of both disability and ability, which in turn guide environmental structures, social organizations, and institutional practices, create barriers for certain individuals, who by nature of their culture and environment are rendered as having “disabling differences” (Adams et al., 2015, p. 8). The cultural model of disability, also known as the biocultural model, explores the subjective, individual interpretations of disability. This model focuses on the relationship between body, society, and culture to honor the experience, impressions, and narrative of the individual (Adams et al., 2015, p. 9). According to the cultural model of disability, the disability experience “does not come either from bodily impairment or from the socially constructed world outside,” but rather the cultural context in which one is situated (Adams et al., 2015, p. 9).

There are a multitude of models and conceptual frameworks that influence how we understand, process, and interact with disability. Thus, our personal and cultural definitions of “disability” tend to vary. An individual’s perception and construction of
disability, identity, and narrative is reflective of their experiential, physical, and attitudinal experiences and in the same vein this renders them malleable. For both individuals with disabilities and individuals without disabilities, manufacturing a more progressive, inclusive, and empowering relationship with disability can improve our broader, ableist disability narrative.

Invigoration of disability pride, the expansion of the disability studies field, and the evolution of person-centered services have contributed to positive gains in disability rights (Haller, Dories, and Rahn, 2006). However, ableism is still the predominant force that dictates how we understand disability as evidenced in our ingrained disability stigma, our inaccessible institutions, and our exclusive systems. Ableism explains why we live in a society of staircases. Today, young adults with disabilities are tasked with physically and ideologically challenging our bevy of staircases and advocating for ramps. In order for young adults with disabilities to navigate systems, transitions, and find worthwhile purpose, they must challenge ableism and redefine disability through a “new disability discourse” (Corker, 1998 as cited in Haller et al., 2006, p. 66). Through exercising agency, youth with disabilities can become activists for inclusion, access, and opportunity; reclaim their personhood and power through advocacy; and improve our world.

**Interpreting Disability**

Our ableist cultural narrative of disability is reflected, echoed, and asserted as fact via every facet of our institutions, systems, and society. In the domains of education, employment, health care, our legal system, accessing housing, establishing relationships, and portrayal in and exposure to the media, we define individuals with disabilities as
being habitually codependent. We frame “having a disability” as being synonymous with “living with limitations.” The prevalence of ableist practices reveals that culturally we do not recognize “disability” as being a community and we do not discuss the disability experience in a phenomenologically authentic, historically accurate way. Disability is always a diagnosis. We accept disability in our lives as a charitable cause and individuals with disabilities are routinely viewed as docile recipients.

Our ableist narrative is bolstered by our ableist historical account of disability as well. The triumphs of disability advocates, landmark gains for the Disability Rights Movement, and examples of expanding inclusive practices often remain untold or subject to dilution. Ultimately our services, structures, and programs rob the disability community of power and denying disability history erases an impressive legacy. Finally, our stigmatized understanding of disability hinders the development of a positive and efficacious disability identity. Supporting youth with disabilities as they become agents of change will simultaneously result in confronting stigma and prejudice. As more youth with disabilities accomplish their goals, the ableist definition of disability will be replaced by the achievements, raised expectations, and empowered words of those living with disability every day.

**Validating the disability experience.** Women and gender studies programs and African American studies programs are fairly recent academic additions at colleges and universities. The inception of these programs acknowledges that these marginalized groups have different perspectives and have experienced different histories compared to dominant culture. The existence of these programs affirms that learning about this community is both important and worthwhile. It ensures that this oppressed group is
remembered accurately historically and they are not purposefully forgotten in the future. The institutionalization of a minority group’s story says, “you exist and your struggles and triumphs are real. With increased visibility and educational efforts hopefully oppression will not always be a part of your experience.”

The “first wave” of disability rights activism that sparked during the 1960s generated legislative, political, and social change. This demonstration of activism influenced the field of academia to interpret disability as a “form of embodied difference that could be studied similarly to race, gender, ethnicity, and sexuality” (Adams et al., 2015, p. 2). However even though disability studies programs are starting to appear at institutions of higher education, “disability studies” is a relatively foreign concept to most people (Davis, 2015 as cited in Adams et al., 2015, p. 63). We are only just now beginning to realize that the disability experience is robust, intricate, and very much a part of our history (Davis, 2015 as cited in Adams et al., 2015, p. 62).

**Respecting disability culture.** Despite a lack of disability education programs, we instruct teachers, doctors, and other professionals to work with youth with disabilities on a daily basis and we assume they are comprehensively prepared to do so. Societally speaking, we do not fully understand disability culture, the every day experiences of individuals with disabilities, the historical context and significance of disability, nor do many people recognize the term “ableism.” Without this background it is difficult to process why we need to better understand disability, explain disability, support and empower people with disabilities, and include people with disabilities in every day life while respecting them as independent people. There is a definite need for more resources
for practitioners and youth with disabilities who can prompt productive discussions on
disability from a personal, educational, historical, professional, and medical standpoint.

**Nurturing disability narratives.** The lack of comprehensive educational,
historical, and instructional context for disability perpetuates the utilization of ableist
narratives to frame disability. This often results in the development and distribution of
materials that borrow themes and core principles from the medical model and charity
model of disability. Haller, Dorries, and Rahn (2006) described these narratives,
specifically examining their prevalence in the media, as syrupy and infused with pity that
served to undermine disability identity. The late disability advocate Stella Young (2014)
coined the term “inspiration porn,” to categorize this misrepresentation of disability.
Young (2014) explored how *inspiration porn* exemplifies our culture’s translation of
disability as being inherently negative, innately less-than, automatically dependent, and
deserving of pity. As the medical model offers to fix the “disabled body” in the pursuit of
making it “normal” (Davis, 2015; Price, 2015 as cited in Adams et al., 2015, p. 63 - 64),
the charity model explains disability through the lens of dependence, and *inspiration
porn* negates portrayals of authentic disability empowerment, their amalgamation
provides a solid foundation to propel, promote, and protect ableism. Our ableist narrative
will not be deposed until individuals with disabilities can practice agency, redefine
disability, and author a new replacement narrative.

**Foundation for My Work**

**Conscientious reflection and narrative.** Given the abundance of disability
paradigms and a rampant misunderstanding of disability, it is not surprising that many
youth with disabilities struggle to understand a diagnosis, advocate for accommodations,
and simultaneously defend being different. For youth with disabilities, being able to explain their disability and how it impacts various aspects of their life is an important and challenging step towards effectively and interdependently navigating our everyday world. Learning how to advocate and exercise agency as well as develop self-awareness are skills that take energy and practice.

Conscientious reflection is a meaningful process that can provide young adults with disabilities the opportunity to reflect on their identity, their disability, and their capacity for agency. This process affords individuals an analytical space to reflect, rehearse, and edit their personal narrative. Through reflection a young adult with a disability can shape their identity as a causal agent who can effectively navigate life experiences in order to attain personal goals. Sustaining agency requires a young adult to maintain a self-identity that is congruent with their motivations and values as well as frame their pursuits as both attainable and worthwhile. Conscientious reflection, especially when integrated into functional youth-adult partnerships, also affords youth with disabilities the opportunity to work towards community improvement goals. Thus, conscientious reflection can be utilized to expand advocacy, support experimenting with activism, and challenge ableism.

The narrative process has become a recognized and effectual tool to help people from all walks of life cognitively reframe experiences, establish goals, and understand their ability to make internal and external changes. Through conscientious reflection we can conceive ourselves as agents and with narration we can edit our self-stories to redefine our effectiveness as agents. However, first we need to forge opportunities for new voices to be heard.
Youth-adult partnerships. Youth-adult partnerships provide a safe space for both parties to learn, collaborate, and practice goal setting as individuals and community agents of change. Through an instructional and supportive youth-adult partnership, young adults with disabilities can learn how to advocate in education, environment, and healthcare settings, practice problem solving and decision making, and appreciate their accomplishments as agents and not resign themselves to living as a diagnosis. These are significant steps towards cultivating an empowered, autonomous disability identity. Reclaiming personhood and power is vital.

Improving the quality of life for people with disabilities means letting them define their identity, activate their agency, and through it all tell their own story that inspires them to give their own lives quality. Ultimately, in order to be effective causal agents who can make successful transitions, young adults with disabilities need dedicated space to determine where identity and disability overlap, practice advocacy and activism, experiment with goal-setting and problem solving, and engage in youth-adult partnerships.

The strong underlying themes of dependency and inferiority in our ableist disability narrative are resoundingly toxic. We are a diverse community and authentic partnership is the only way we can all collectively succeed, but the key word is authentic. The relationship between people with disabilities and neurotypical, able-bodied individuals needs to be an equal-status partnership. As we simplify the personification of the disability-ability dynamic to a person who habitually needs help and a person who feels obligated to help, disability becomes synonymous with inability. Creating equal-status partnerships that prioritize two-way learning and reciprocal benefits can shape how
we practice empathy, exercise agency, understand diversity, and commit to social justice. Disability does not mean less than. Disability does not mean powerless. Disability is just difference.

Exploring Disability-Positive Frameworks

Agency. I stipulate that promoting agency will lead to empowerment and ultimately nurture a new disability story in which people with disabilities, in an authentic partnership with other individuals who in turn have their own diversity stories, work together to produce the changes our community needs. Currently our societal disability narrative glosses over the complexity of inclusion and the need for nurturing new voices and new activists. I refer to a suggested counter narrative as a “disability-positive framework” in which language, media images, literature, historical accounts, curriculums, programs, services, etc. honor the phenomenological experience and personhood of young adults with disabilities. Under this framework any symbols, themes, and resources that amplify individual voices in a respectful, authentic, and comprehensive way are examples of “disability-positive content.”

The disability-positive framework and disability-positive content explore the social and cultural models of disability; encourage intentionally constructing a relationship between identity, disability, and agency through distinct narrative; and state that young adults with disabilities need to establish and accomplish meaningful goals. Finally, this framework and content come to life through the construction of “disability-positive environments.” Disability-positive environments foster skill building, provide advocacy opportunities, and support youth with disabilities as they explore their self-efficacy and establish goals within a safe, culturally competent, and inclusive framework.
Ideologically this system maintains high expectations and promotes authentic learning for youth with disabilities who are framed as autonomous, agentic leaders. Overall disability-positivity demands authenticity, autonomy, agency, and genuine accomplishment.

**Inclusion.** We are making progress creating a culture that respects the diverse spectrum of the human condition as reflected in changes in our health care system, educational institutions, adapting social norms, supports provided through our human service systems, and in our establishment of inclusive practices across systems. By providing young adults with disabilities opportunities to explore disability-positive resources and time to construct their own identities and set their own goals, the disability narrative is enriched by new experiences and new perspectives. This also contributes to our ever-evolving definition of inclusion that must reflect the needs and priorities of those directly impacted.

However, the truth remains that adults with disabilities still struggle significantly with financial independence (Field, Sarver, and Shaw, 2003), students with disabilities still encounter challenges securing accommodations in work and school that lead to negative transition experiences and self fulfilling prophecies of failure (Scholl and Mooney, 2004), and young adults with psychiatric disabilities have high rates of hospitalization due to social isolation and the influences of unhealthy relationships (Kaplan, Salzer, and Brusilovskiy, 2012). Our community needs to keep working together, both people with disabilities and neurotypical, able-bodied individuals. True inclusion means that people with disabilities contribute to and are also responsible for the work that is needed to make our world accessible.
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**Social justice.** Ultimately, we cannot settle for superficial engagement in this matter of social justice. We need to provide young adults with disabilities access to resources, experiences, and opportunities that will help them develop their own identities as causal agents who can accomplish their goals—while having a disability. Young adults with disabilities need to find their voice so they can lead their own lives and contribute to a new disability narrative that is robust, honest, and comprehensive. Our understanding of disability cannot continue to be nourished by the tenets of ableism, the medical model of disability, the charity model of disability, and *inspiration porn.* The low expectations and poor transition outcomes that have become synonymous with disability must be challenged in order to produce positive social change.

**Research objective.** My dissertation addresses severing our cultural attachment to ableist doctrine by changing how we frame disability by exploring disability-positivity. Encouraging young adults with disabilities to construct personal narratives concerning their identities, their disabilities, and their goals will result in young adults who believe in the efficacy of their own agency. They can tell their story in a voice that is uniquely their own but more importantly they can act on their values, objectives, and accomplish their goals. This will make the disability narrative a story of resilience, autonomy, and more importantly, it will fold “disability” under our definition of “normal.” Disability then becomes an everyday, unexceptional detail. Until we support young adults with disabilities in their own authentic storytelling, our community will not honor their perspectives and they will struggle to be actors in their own lives. Changing how youth with disabilities see themselves and concurrently understand their capacity for action is
an investment in a generation of young people who not only practice self-care but stewardship of the world.

**Call to the Work: Personal, Educational, and Professional Experiences**

My dedication to disability studies and my commitment to improving service systems through educational practices both stem from a variety of experiences and influences. Disability impacts so many people on a personal level; whether it is a family member, a dear friend, or living with a personal disability, the disability experience is one that many are familiar with and this relationship often inspires action and empathy. Similarly my interest in pursuing this field was born of my personal relationship with disability, having been diagnosed with bipolar I disorder as a teenager. After graduating with a B.A. in psychology, a Masters of Science in Special Education, investing countless hours volunteering with advocacy groups, garnering professional experiences as an education advocate, working as a college disability services coordinator, and working as a youth program coordinator at the Children’s Hospital of Pittsburgh of UPMC, I felt relatively well-rounded as an educator, an advocate, and a specialist in youth development in the disability community. However authentic learning is never finished and with the desire to further inform my leadership and strengthen my effectiveness when working within systems, I returned to school for my doctoral degree.

Throughout my professional and educational journey I have met many young people with disabilities who, like me, have buoyed in a rough, confusing sea of disability versus identity. These young people, like me, are all exploring what disability means in relation to who they are, reconciling their goals pre-diagnosis and post-diagnosis, navigating systems not always designed to help them, overcoming stigma and shedding
stereotypes, and trying to write their own authentic stories that they edit as they evolve. My disability journey has been professional, educational, and personal and it is far from over. My ability to be a humble learner, an eager student, a loving wife, a caring daughter, a supportive sister, a compassionate friend, and a dedicated writer has revolved around my ability to see myself as an effective causal agent—someone who is capable of achieving her goals and effectively managing her own self care in order to live the life she chooses.

My interest in working with young adults with disabilities has covered the spectrum of the conventional education realm to the medical field. In each of these fields through each of these positions I have worked with a diverse group of stakeholders, primarily young adults with disabilities, to create environments that value empowerment, collaboration, disability-positive attitudes and actions, leadership development, and educational growth. A highly formative experience that enabled me to first begin operationally defining a disability-positive environment was my year spent working at the Children’s Hospital of Pittsburgh of UPMC. My position focused on designing, operationalizing, and sustaining a youth leadership and advocacy group geared towards supporting young people with a variety of disabilities as they became both agents in their own lives and peer educators.

Empowering youth with disabilities to be confident self-advocates, competent activists, and responsible contributors in youth-adult partnerships requires agency. To challenge how we think about disability and curtail our tendency to disempower people assigned labels, we need to equip our young people with the right resources, tools, and safe spaces to practice being autonomous individuals. Whether it is manifested somewhat
subtly in media (Haller et al., 2006; Young, 2014), reinforced in classrooms (Price, 2015 as cited in Adams et al., 2015, p. 64), or medicalized in examining rooms (Davis, 2015 as cited in Adams et al., 2015, p. 63), we need our ableist narrative to be replaced with the powerful messages from those who live with disability everyday.

Replacing our outdated and corrosive ideas on disability with a disability-positive framework that amplifies the voices of the disability community will contribute to a louder call for transparency. People of all abilities can set goals, achieve their goals, and influence their environment, but this requires opportunities for self-exploration, conscientious reflection, and experimenting with agency. I argue that challenging the medical model of disability, examining the charity model of disability, deconstructing inspiration porn, and extinguishing ableism will improve outcomes for youth with disabilities. In order to eradicate these harmful ideologies we need to deliberately craft and implement a disability-positive framework that amplifies individual voices, supports problem-solving, encourages goal-setting, and provides opportunities for youth-adult partnerships with emotional scaffolding for all stakeholders.
Chapter 2

The Problem and the Problem of Practice

Experiencing Disability: Literature Review

Young people with disabilities struggle to become independent, healthy, successful adults because they have a significantly harder time graduating from high school, completing a college degree, and securing gainful employment compared to their peers without disabilities. This results in higher rates of poverty, lack of safe and affordable housing, and restricted access to healthcare for members of the disability community. In addition, our current systems fail to practice true inclusion, which results in youth with disabilities being isolated and segregated from recreational and social opportunities. How we culturally conceptualize disability and how we have constructed our institutions and systems leaves youth with disabilities considerably more likely to experience isolation, exclusion, and poor quality of life.

Access: A Critical Component

Education and employment. When youth with disabilities graduate, age-out, or otherwise leave high school there is a sizeable and sudden gap in services, which makes the transition into adulthood particularly hard. In addition to fewer available resources, service delivery is often designed to support minors and advertised to guardians. When youth with disabilities become legal adults this assumed increased capacity leads to more opportunities to make decisions, including electing to apply for or stay enrolled in disability-based programs, a decision undoubtedly influenced by stigma. Advocacy resources and opportunities to build vital independent living skills are also not available to all young people with disabilities. The lack of adequate services provided during
school and the disruption or discontinuation of services after high school results in detrimental consequences for youth with disabilities. Due to these reasons young adults with disabilities have significantly poorer post high school outcomes in education, employment, healthcare, and overall quality of life.

Individuals with disabilities struggle to meet typical education and employment milestones. Over one-third (37%) of students with a mental health condition age 14 – 21 who are enrolled in special education drop out of school (U.S. Department of Education, 2014). According to the U.S. Department of Education, in the late 1990s only 25.5 percent of students with disabilities graduated from high school with a standard diploma (U.S. Department of Education, 2000 as cited in Adams et al., 2013. Similarly, young adults with disabilities are more likely to graduate from high school by passing a General Education Development exam or by attending an alternative high school than matriculating after four years (U.S. Department of Health and Human Services, 1999). When it comes to college, while 55% of young adults with disabilities were enrolled in postsecondary education after high school in 2011, only 38% actually completed their education (Sanford, Newman, Wagner, Cameto, Knokey, and Shaver, 2011).

As of 2013, individuals with disabilities in the United States were “five times more likely than able-bodied people to be unemployed and were disproportionally likely to be employed-part time” (Rose, 2015 as cited in Adams et al., 2015, p. 188). People with disabilities have a persistently lower rate of employment and noticeably lower salaries (Barber, 2012). In fact, in comparison to the 76.3% employment rate of individuals without disabilities, the employment rate of people with disabilities is only 33.5% (Erikson, Lee, and von Schrader, 2014). Limited opportunities for employment
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often predestine individuals with disabilities to working in sheltered workshops where they are systematically paid lower wages. For example, the Fair Labor Standards Act of 1938 exempted some sheltered workshops from paying employees the minimum wage and as of 2011, an estimated 426,000 employees with disabilities work for wages as low as 41 cents per hour (Rose, 2015 as cited in Adams et al., 2015, p. 189).

Higher functioning young adults with disabilities who have requisite skills for competitive employment can fare well, especially when assisted by reasonable accommodations. However, researchers Scholl and Mooney (2004) found that when youth with disabilities have difficulty securing workplace accommodations this predictably leads to negative experiences. This accompanying fear of failure can often translate into a self-fulfilling prophecy of underachievement (Scholl and Mooney, 2004). Many individuals with disabilities rely on means-tested benefit programs, like Supplemental Security Income and Medicaid, but eligibility for these services is based on financial need (Rose, 2015 as cited in Adams et al., 2015, p. 189). In most instances the criteria for “financial need” requires an income close to if not below the poverty level (Rose, 2015 as cited in Adams et al., 2015, p. 189). Due to decreased opportunities for gainful employment and health care that is contingent on maintaining a low income, many individuals with disabilities have an increased likelihood of poorer health status, living in poverty, and being isolated from their peers (Newacheck, 1989).

Accommodations. The definition of access, within the context of disability, demands that integration and inclusion are made possible via institutional and material changes (Williamson, 2015 as cited in Adams et al., 2015, p.15). Therefore access is “not dependent on correcting the disabled body” but ensured through the provision of
reasonable accommodations (Williamson, 2015 as cited in Adams et al., 2015, p. 15). However, I must contribute to this definition by adding that sustainable access can only be realized if we challenge our attitudinal assumptions regarding disability and shift our thinking and level of accountability from inclusion to full-fledged integration—from passive awareness to active acceptance—and focus on making experiences and opportunities engageable as well as accessible. The social and cultural models of disability dictate that social justice and social progress are hinged on the development of widely adopted and actively enforced social and legal solutions to systemic barriers (Williamson, 2015 as cited in Adams et al., 2015, p. 15). This demands a departure from approaching lack of access as an individually situated problem, which in turn requires a paradigm shift in our cultural conceptualization of disability and the right for disability to exist in public spaces (Williamson, 2015 as cited in Adams et al., 2015, p. 15).

Difficulty securing accommodations, inaccessibility, an overall lack of opportunities, and damaging attitudinal barriers are all factors that can potentially obstruct youth with disabilities as they transition to independent adulthood. Ultimately, “adults with disabilities are less successful in seeking and maintaining employment, achieving a satisfactory standard of living, developing independence, and other quality-of-life indicators than persons without disabilities” (Field, Sarver, and Shaw, 2003, p. 339). Unfortunately having a disability, as with membership in any marginalized group, can present a plethora of disadvantages and inequities. In order to fully participate in society you first need access to the mechanisms of everyday life and have the ability to influence systems. Contributing to society means you are able to leverage your power and make positive individual changes as well as have community impact. Unfortunately
people with disabilities live in a world where accessing life is contingent upon securing accommodations—accommodations that are only necessary because our world was built by a powerful, dominant culture that did not create equitable space for marginalized groups. It is alarmingly clear that our current infrastructure favors people who are neurotypical and able-bodied and requires anyone who deviates from the norm to request accommodations to access the same opportunities (Adams et al., 2015).

**Access as an aspect of citizenry.** The fight for access, opportunity, and inclusion in everyday life is a battle that has developed traction over time. In the United States the Disability Rights Movement first gained visible and notable momentum in the 1960s (Haller et al., 2006). Disability studies scholars acknowledge that the Civil Rights Movement helped pave the way for the Disability Rights Movement, which gained momentum as individuals with disabilities began to view themselves for the first time as oppressed minorities being denied their constitutional rights (Adams et al., 2013). The acceleration of this movement was fueled not only by the fact that the federal government did not consider individuals with disabilities a distinct “class” that was entitled equal rights under the law but also this explicit discrimination helped solidify a distinct disability culture that spawned community, power, pride, and visibility (Adams et al., 2010).

Access has always been a key pillar of the movement and in 1975 legal advocates Marcia and Robert Burgdorf linked access to fundamental American liberties. In their landmark argument they stated that access to public buildings and transportation systems is a protected legal right for individuals with disabilities (Burgdorf and Burgdorf, 1975). Their argument that accessible public transportation and access to public institutions is a
federally protected right placed the burden of accessibility on the government and not the individual. Similarly the widely respected Convention on the Rights of Persons with Disabilities stipulates that ensuring access for all citizens should be listed among a country’s top priorities. The Convention on the Rights of Persons with Disabilities emphasizes that individuals with disabilities need to be granted the inalienable rights of “autonomy, dignity, and freedom of choice” as well as services and opportunities that promote “independent living, community inclusion, access, and mobility” (Hendriks, 2007 as cited in Stylianos and Kehyayan, 2012). Disability studies scholars assert that the ability of individuals with disabilities to access what they are entitled to, on an equal basis with others, is the clearest reflection of the extent to which they are considered valued citizens (Sabatello, 2015 as cited in Adams et al., 2015, p. 158).

Financial opportunity. In addition to physical access to our societal landscape, individuals with disabilities need accessible opportunities to maximize their financial capital. In our capitalist culture, all citizens should have the opportunity to increase their earning potential and investments. However in regard to creating accessible employment opportunities and accessible work environments many employers harbor concerns that accommodations are costly and an overall impediment to productivity (Emens, 2015 as cited in Adams et al., 2015, p. 19). Historically, “disability has been characterized as the inability to do productive labor,” which to this day negatively impacts the social standing and citizenship of individuals with disabilities (Rose, 2015 as cited in Adams et al., 2015, p. 187). Interestingly enough, data collected by Schartz, Hendricks, and Blanck in 2006 (as cited in Emens, 2015, p. 19), the Job Accommodation Network (2014), and Adams et al., (2010) suggest that more than half of all workplace accommodations cost nothing. An
even more revealing fact is that the human cost of exclusion is rarely factored into the equation (Sabatello, 2015 as cited in Adams et al., 2015, p. 159). The “loss of wages, income taxes, and public assistance expenses due to the exclusion of persons with disabilities costs far more than accommodating them in the workplace”—a potentially game-changing statistic that unfortunately is seldom considered (Sabatello, 2015, as cited in Adams et al., 2015, p. 159).

The reality is that there is not one identifiable factor that causes young adults with disabilities to experience difficulty navigating the adult world, but many compounding variables. For individuals with disabilities, not being able to live independently; limited access to transportation; insufficient financial opportunities; fewer educational trajectories that lead to higher education or purposeful employment; restricted access to comprehensive, holistic, and patient-directed medical care; limited opportunities to connect with peers and nurture friendships; and a shortage of opportunities to make autonomous decisions about things that matter are all significant barriers that contribute to the negative reality of our young adults with disabilities. Having a disability often destines an individual to a quality of life that is determined by their ability to effectively access accommodations.

**Agency and Stigma**

Fundamentally many of the barriers young adults with disabilities experience are the product of an ableist cultural narrative that focuses on the prejudiced assertion that disability means inability (Love, 2015 as cited in Adams et al., 2015, p. 173; Peters, 1999 as cited in Haller et al., 2006). Stigma hinders successful employment and educational experiences, mars social recognition, negatively influences friendships and sexual
relationships, restricts access to housing, and can expose people to violence (Love, 2015 as cited in Adams et al., 2015, p. 173). The manipulation of stigma and stereotypes makes it easier to dismiss people with disabilities and it frees society from feeling a sense of urgency, responsibility, or obligation to provide support (Byrne, 2000, p. 66). Thus the self-perpetuating cycle of disability disempowerment rages on as we continue to create a world where those with disabilities often struggle and fail and this failure is then held as evidence that disability indicates inferiority. In sum, under the guise of ableism, disability is misrepresented as we focus on blaming the “broken” individual rather than acknowledging and fixing the flawed system. This toxic narrative impacts young adults with disabilities who are prone to carve out identities that incorporate a perceived inherent ineffectiveness and inability to make positive changes.

Due to the many negative conceptualizations of disability and societal pressures to “fit in” and be “normal,” it is imperative that we equip our young adults with disabilities with the skills, resources, and opportunities they need to develop a strong sense of self. The ability to push back on stigma and redefine ability is vital (Peters, 1999 as cited in Haller et al., 2006). Our current ableist narrative of disability conditions young adults with disabilities to believe that agency, and thus the ability to make positive changes in their lives, is not a part of their story. Our youth with disabilities are caught in a vicious cycle. They live in a society that does not expect them to become independent adults, which leaves them struggling with underdeveloped agency and grappling with imposed low expectations. Living in the shadow of anticipated codependence clearly has debilitating consequences but it is a deeply rooted and complicated problem to solve.
Disability and Inalienable Rights

For members of marginalized communities, harmful signifiers of oppression are the denial of power and being caught in a biased legal system where your voice is neither heard nor respected. This is often best articulated by critical race theorists, like legal scholars Brooks and Newborn (1994), who state that critical race theory focuses on the ways that our legal system adversely affects people of color not as individuals but as a group. Similarly, individuals with disabilities are subjected to living in a legislative system that has traditionally made equitable access unobtainable, authored laws designed to protect inclusion and prevent discrimination that are chiefly complaint driven, and failed to give credence to the needs and rights of individuals with disabilities as citizens. This struggle to access resources, secure opportunities, experience equality, and gain rights as citizens of the United States is a well-known battle waged not just by African Americans and individuals with disabilities but also women, the LGBTQIA community, and other people of color. The denial of rights has led to a plethora of social justice movements and persuasive acts of activism.

In our current world, “individuals are assumed to possess rights simply by virtue of being human” (Sabatello, 2015 as cited in Adams et al., 2015, p. 158). Human rights are defined as inalienable, universal, and reflective of personhood, thus they cannot be withheld and withdrawn by systems of power (Sabatello, 2015 as cited in Adams et al., 2015, p. 158). In other words states, governments, and private sectors do not have the authority to retract or deny human rights. The civil rights movements that have shaped our legislative landscapes have all waged battles to gain societal, political, and economic recognition, establish equality for all people, and particularly liberate minority groups
from oppressive systems and power differentials (Sabatello, 2015 as cited in Adams et al., 2015, p. 159-160). In a society of silos the challenges associated with these movements are often exacerbated by our cultural tendency to compartmentalize differences, which restricts access and collaboration between marginalized communities. These categorizations often become rigid as they segregate different marginalized groups, reinforce these demarcations via stigma, isolate these issues under the misnomer of “single-issue struggles,” and hamper conversations on intersectionality.

Beginning of disability activism. Disability activism first gained recognition in the late nineteenth and early twentieth centuries as individuals with disabilities, angered by restricted freedoms, formed associations to fight for economic rights (Nepveux, 2015 as cited in Adams et al., 2015, p. 22). Their successful strategies and objectives were actually modeled after trade union struggles (O Cathain 2006 as cited in Nepveux, 2015, p. 22). In the 1960s, a cross-disability Disability Rights Movement was launched in order to gain cultural and legal acknowledgement (Haller et al., 2006). This movement mobilized to secure civil rights, equal access, and inclusion throughout the 1960s and 1970s by arguing that access to education, employment, housing, and transportation were intrinsic human rights (Adams et al., 2015, p. 2). Similar to utilizing trade union strike tactics in disability activist efforts in the early twentieth century, members of the disability community informed their own activism in the 1960s and 70s by witnessing and participating in the social justice movements spearheaded by other marginalized groups (Nepveux, 2015 as cited in Adams et al., 2015, p. 22). The Civil Rights Movement, the Black Power Movement, the Feminist Movement, and other examples of collective action “exposed men and women with disabilities to tactics of protest and
enabled them to begin recognizing and questioning violations of their human and civil rights” (Nepveux, 2015 as cited in Adams et al., 2015, p. 22).

This momentum also spawned the Independent Living Movement in the late 1960s, which materialized through the development of Centers for Independent Living (Kittay, 2015 as cited in Adams et al., 2015, p. 56). The prime objective of the Independent Living Movement is affording individuals with disabilities control over their circumstances in regard to transportation, living arrangements, education, employment, and inclusion in both social and familial life (Kittay, 2015 as cited in Adams et al., 2015, p. 56). Centers for Independent Living are non-profit agencies staffed both by individuals with and without disabilities that provide services to empower individuals with disabilities to live at their “highest achievable level of independence” (Three Rivers Center for Independent Living, 2015). These organizations advocate that individuals with disabilities need the right resources and appropriate level of support to become the primary decision-makers in their own lives (National Council on Independent Living (NCIL), 2015). Through commitment to individual advocacy and systemic activism, Centers for Independent Living have inspired many grassroots movements and challenged attitudinal barriers surrounding disability across the country (NCIL, 2015). The Independent Living Movement continues to champion independence and access for people of all abilities (NCIL, 2015).

**Activism and legal action.** Legal action addressing accessibility was eventually put in motion with the creation of Section 504 of the Rehabilitation Act of 1973, which fought to prohibit discrimination based on disability status. However, the federal government delayed implementing and enforcing these regulations until 1977 after
organized protests by the disability community gained national attention (Nepveux, 2015; Brune, 2015 as cited in Adams et al., 2015, p. 23, 122). The disability activist group, Disabled in Action, led the charge for change and organized sit-ins of federal buildings across the country (Barnartt and Scotch, 2001). Many of these protestors were also advocates in the Independent Living Movement but individuals from all backgrounds and people impacted by disability in a variety of ways participated as an act of support and solidarity (NCIL, 2015). Ultimately while individuals with disabilities led this effort, it was sustained by a diverse group of allies and supporters, including able-bodied individuals and other activists, like members of the Black Power Movement (Nepveux, 2015 as cited in Adams et al., 2015, p. 23).

Another seminal piece of legislation for the Disability Rights Movement was the Americans with Disabilities Act (ADA), which was first adopted in 1990. The ADA made discrimination against individuals with disabilities in the areas of employment, transportation, state and local government, public accommodations, and telecommunications a violation of federal law (FISA Foundation, 2015). Since then the ADA has been revisited to incorporate much-needed updates. In 2008 the definition of disability and what constitutes substantial limitation was expanded in order to comprehensively reflect the needs of a diverse disability community (Adams, et al., 2010). In 2009 the ADA Amendments Act was revised to extend additional protection to employees with disabilities who requested reasonable accommodations from their employer (Rose, 2015 as cited in Adams et al., 2015, p. 189). This legislation also protected employees with disabilities who filed discrimination complaints against their employers for unmet accommodations (Rose, 2015 as cited in Adams et al., 2015, p.
In addition to ushering in the adoption and implementation of Section 504 and the ADA, disability activists were responsible for the passage of the Education for All Handicapped Children Act of 1975, the Individuals with Disabilities Education Act (IDEA) 1990, 1997, and the Individuals with Disabilities Education Improvement Act (IDEIA) 2004 (Adams et al., 2010). Laws were finally being passed and enacted that made access, opportunity, and inclusion more of a reality for individuals with disabilities, and most importantly protected the rights of individuals with disabilities.

Visibility for the disability community. A history of activism and subsequent legislative triumphs not only secured protection under the law for individuals with disabilities but also increased visibility in society. Mainstream society witnessed the disability community as a proud and determined coalition of advocates and activists. Legal victories were won and attitudinal barriers surrounding disability were challenged. Notable disability rights protests such as the Capitol Crawl and the Section 504 protests explicitly disrupted daily life for government employees. During the Capitol Crawl, wheelchair users abandoned their mobility aids to crawl up the grossly inaccessible steps of the Capitol building (Imrie, 2015 as cited in Adams et al., 2015, p. 172). During the Section 504 protests activists staged hunger strikes in various government buildings across the country (Imrie, 2015 as cited in Adams et al., 2015, p. 172). These organized and effective demonstrations were held in response to the significant delays of the passing of the Americans with Disabilities Act (1990) and delayed implementation of provisions of Section 504 of the Rehabilitation Act of 1973 (Imrie, 2015 as cited in Adams et al., 2015, p. 172). In addition to visible public action, a major triumph for disability activists during the creation and adoption of the ADA was that the law
maintained the narrative of civil rights and minority group politics (Watson, 1993 as cited in Haller et al., 2006). The ADA claimed equal rights for individuals with disabilities not as recipients of charitable obligation, but as citizens. Individuals with disabilities were exercising their capacity for agency and demanding their rights as equal citizens who should be both seen and heard.

Our definition of “disability” has long been associated with passivity and docility. Disability is often viewed as a condition resulting in codependence of “people with ability.” However the prominent and intentionally controversial disability rights organization, the American Disabled for Accessible Public Transit (ADAPT), challenges this ableist narrative. Starting in the 1980s ADAPT staged protests and rallies demanding access to public transportation and highlighting our nation’s discriminatory structures and systems (Imrie, 2015 as cited in Adams et al., 2015, p. 172). This group was led by a multitude of outspoken leaders who translated their experiences with inaccessibility and exclusion into public action. Currently ADAPT leaders, like Mark Johnson, lecture on their approach to activism and propagation of a disability-positive paradigm. Johnson was invited to present at the Thornburgh Lecture Series at the University of Pittsburgh in October 2015 as the keynote speaker on the topic of the Americans with Disabilities Act (FISA Foundation, 2015). At this event local political figures, academics, service providers, students, families, and other members of the Pittsburgh community celebrated Johnson’s contributions to the Disability Rights Movement and his efforts towards increasing equality for people of all abilities.
The Practice of Leadership

The actions and fortitude of countless disability activists have ushered in a breadth of necessary changes in our country. As with most movements, enlisting the energy, support, and action of young adults remains pivotal in sustaining gains in social justice. The Rolling Quads was a student activist group at the University of California, Berkley, in the early 1960s demanding equal access to education and new models of user-controlled, person-centered services (Nepveux, 2015; Price, 2015 as cited in Adams et al., 2015, p. 22, 65). The Rolling Quads consisted of students with severe physical disabilities who were the first generation of “disabled youth” allowed to attend public schools. They now demanded access to a college education (Nepveux, 2015 as cited in Adams et al., 2015, p. 22). The group’s primary leader, Ed Roberts, who was paralyzed from contracting polio, was inspired by other manifestations of student activism, like the Free Speech Movement and the Women’s Movement’s refusal of imposed passivity (Nepveux, 2015; Rodas, 2015 as cited in Adams et al., 2015, p. 22, 103). Encouraged by these frameworks, Roberts was able to effectively apply similar tactics to act on the needs of his community (Nepveux, 2015; Rodas, 2015 as cited in Adams et al., 2015, p. 22, 103). The Rolling Quads rolled out access for a diverse student body; challenged stigma through action, presence, and conversation; and Roberts went on to pioneer the Independent Living Movement and serve as the director of the California Department of Vocational Rehabilitation (Ed Roberts Campus, 2015).

Legacy of leadership and agency. Roberts’s energy for activism lasted a lifetime and similar passion, dedication, intentionality, and leadership was practiced by other phenomenal young adult leaders like Judy Heumann, a champion of the Independent
Living Movement (Kittay, 2015; Rodas, 2015 as cited in Adams et al., 2015, p. 56, 103), and Justin Dart, an influential leader in the adoption of the ADA (Rodas, 2015 as cited in Adams et al., 2015, p. 103). These leaders inspired other activists and paved the way for the larger disability community to organize protests, social media campaigns, and advocacy on individual levels. However, as mentioned previously, disability history is not a commonly taught discipline and the disability community’s legacy of activism remains somewhat invisible. Today, individuals with disabilities must still fight for inclusion and command influence over the structures, policies, programs, and laws that dictate access. The disability community must still rally to protect their right to make decisions and defend their equitable place alongside able-bodied peers.

Developing leadership, agency, and effectively practicing activism requires remarkably more than a history lesson that is hard to find. In our everyday environment there are countless instances in which young adults with disabilities are reminded that they do not fit in a neurotypical, able-bodied world. Young adults with disabilities often encounter stigma and prejudice, which can contribute to the development of a negative self-identity. This leads to ineffective agency, diminished self-advocacy, and difficulty participating in important aspects of everyday life like relationships, healthcare, education, and employment (Love, 2015 as cited in Adams et al., 2015, p. 173).

**Exploring identity.** The formation of identity is rooted in how the self belongs or does not belong in social, political, and cultural groups (Rodas, 2015 as cited in Adams et al., 2015, p. 103). The self truly transforms into a “social body” after it becomes socially visible against a backdrop outlining where and how it fits in the world (Rodas, 2015 as cited in Adams et al., 2015, p. 103). Young adults with disabilities are entitled to cultivate
their own understanding of identity, their own understanding of disability, and how this impacts their navigation of life transitions. It is of utmost importance that we empower youth to define who they are—the cerebral self and the body—and encourage them to challenge their social, political, and cultural backdrop through their own narrative. In order for youth with disabilities to have the same opportunities offered to neurotypical, able-bodied peers, we need to support young adults with disabilities as they begin to shape their own identities and practice agency.

If we want our young adults with disabilities to go to school, work, be active in their community, and make important decisions in self-care, we need to provide opportunities for conscientious reflection and narration. Many researchers have substantiated that there are a multitude of documented, measurable, and quantifiable advantageous effects of the narrative process, conscientious reflection, meditation, and mindfulness (Bandura, 1989, 2001; Pennebaker, 1999, 2006; Wilson, 2004). Deplorable poverty rates and low quality of life standards for people with disabilities will not improve unless young adults with disabilities are provided opportunities to explore the positivity of the self, the effectiveness of their advocacy, and the power of their own agency.

Agency empowers young adults with disabilities to take advantage of opportunities that could substantially improve their quality of life. When more young people with disabilities experience success, there is greater potential to change our ableist definition of disability. Young adults with disabilities do not have to depend on systems but can positively influence systems; having a disability does not preclude being a productive person. However, without a way for young adults with disabilities to cultivate
their own identity, one that incorporates disability and agency, they will struggle to become autonomous individuals who can not only navigate a neurotypical, able-bodied landscape but also make our world more inclusive. If we want to improve education statistics, employment rates, income level, healthcare outcomes, and quality of life for the disability community we need to provide resources and opportunities that foster the creation of personalized, empowering, and positive definitions of disability.

**Our Culture of Compliance and Codependence**

Our cultural expectation for compliance and co-dependence in regard to youth with disabilities begins at an early age. Whether a child is identified as having a disability through school-based initiatives like Child Find, or they are diagnosed by a healthcare provider, the purpose of these practitioner relationships is finding and fixing a problem (Price, 2015 as cited in Adams et al., 2015, p. 64). For young people with disabilities, relationships with teachers and clinicians can be highly seminal as schools and doctors’ offices are routinely frequented during childhood and adolescence. Experiences in education and healthcare can significantly impact youth with disabilities during their formative adolescent years. In both settings we explain normalcy as an objective, static metric. “Normal” is derived from the Latin word “norma,” which means T-square, and “normalis,” which means perpendicular. Normal is thus the rule and measurement we use to right, straighten, and “impose a requirement on an existence” (Canguilhem, 1978, p. 239). In the classroom and examining room we measure children in comparison to the desired “normal” and those results dictate what interventions an adult system can exact on developing bodies and minds (Titchkosky, 2015 as cited in Adams et al., 2015, p. 131; Adams et al., 2010).
**Classroom.** In the United States, “the classroom is often imagined as an important setting for [disability] interventions and cures to take place” (Price, 2015 as cited in Adams et al., 2015, p. 64). Professional educators are tasked with quantifying learning and achievement, ascribing value to examples of students’ learning and achievement, and enforcing the objective nature of learning and achievement (Titchosky, 2015 as cited in Adams et al., 2015, p. 131). Teachers and school systems are not only responsible for categorizing students’ academic skills but also “classifying, labeling, and sorting so-called deviant behaviors” (Rogers and Mancini 2010). As expressed by Margaret Price (2015 as cited in Adams et al., 2015), different educational settings “use the concept of disability in order to measure attributes such as intelligence, to track and predict performances in order to exploit the differences between ‘gifted’ and ‘slow’ students, and ultimately achieve a variety of segregationist effects whose aim is to uphold existing power structures” (p.65). Disability quickly becomes inability when standards of learning are created based on a “normally” developing child (Titchosky, 2015 as cited in Adams et al., 2015, p. 131). School districts and administrators report that “disability” is the primary explanation for academic challenges, which suggests that for students with disabilities their scholastic achievement is subject to the whims of their diagnosis (Price, 2015 as cited in Adams et al., 2015, p. 66). Diagnoses and letter grades quickly become tangled indicators and predictors of success and failure.

In summation, our education system evaluates students to determine how “a child departs from age-specific norms for walking, talking, thinking, and interacting” (Titchkosky, 2015 as cited in Adams et al., 2015, p. 131) in lieu of exploring the individualized strengths and skills of each student. This process renders learning
impersonal and inauthentic. Our lowered expectations for youth with disabilities and our
citation of disability as a predictor of capability can leave these youth feeling less-than,
passive, and unmotivated. This expectation of passivity and compliance further fuels the
ethos of ableism by perpetuating stigma and negative outcomes for the disability
community. Obviously empowering all students to claim ownership of their ability to
learn is fundamentally important. However for youth with disabilities greeting them at
the schoolhouse door with pre-existing low expectations is just a small part of a much
larger problem.

Examining room. The medical model of disability reinforces passivity through
the patient model, which claims, “all conditions are treatable through medical
intervention” (DasGupta, 2015 as cited in Adams et al., 2015, p. 120-121). When youth
with disabilities personify the role of passive patient, their health outcomes are also
negatively impacted. The ideological principles that guide the process of medical
classification, shape the formulation of medical procedures, and inform the medical
narrative frame disability as a stigmatized condition (Love, 2015 as cited in Adams et al.,
2015, p. 173). In the field of medicine, disability stigma is interpreted as medical
pathology and inferiority (Love, 2015 as cited in Adams et al., 2015, p. 173). When
doctors harbor low expectations for patients with disabilities and simultaneously decrease
the amount of responsibility they have in regard to managing their own care, it results in
diminished agency. In the United States the practice of medicine primes doctors to be the
sole credible experts with the capacity to objectively measure for and cure abnormality
(Titchkosky, 2015 as cited in Adams et al., 2015, p. 131).
The medicalization of disability means that we define and treat disability as an illness or disorder that is relegated to the care of medical professionals (DasGupta, 2015 as cited in Adams et al., 2015, p. 120; Adams et al., 2013. Even when an individual views their disability as nonmedical this personal narrative is surpassed by credentialed medical opinion (DasGupta, 2015 as cited in Adams et al., 2015, p. 120). The “disabled body” falls under the jurisdiction of medical professionals (DasGupta, 2015 as cited in Adams et al., 2015, p. 120), who are “nondisabled agent[s]” trained to cure a broken a body (Rodas, 2015 as cited in Adams et al., 2015, p. 103). According to Titchkosky (2015), we classify medical professionals as the only individuals with the right measuring tools and the right interventions (as cited in Adams et al., 2015, p. 131). While it is obviously true that practitioners are well-trained and well-versed in their fields, we often denigrate a youth’s potential for contributing to their education or health by citing that only professionals have the expertise and authority to make decisions. In order to keep youth with disabilities invested in their education and healthcare we have to make them responsible partners. When one is passive, compliant, and co-dependent their ability to act as a self-advocate and practice self-care is profoundly impaired.

**Equal-status partnerships.** Youth with disabilities struggle to understand themselves as students, patients, self-advocates, agents, and prominent partners in decision-making. In order to support youth with disabilities as they encounter barriers and situations that require independent problem solving, we need to give them not only the necessary resources but also instill confidence that they are capable agents. Confronting disability oppression and challenging ableism is a matter of social justice that requires individuals to develop as competent citizens and empowered agents as
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outlined via the citizenship model (DasGupta, 2015 as cited in Adams et al., 2015, p. 121). The dynamic between teacher-student and doctor-patient—or in other words, adult professional-budding citizen—should be a partnership anchored in reciprocal respect and mutually beneficial opportunities for learning that are reinforced by fluid exchanges of information, reflection, clarification, and understanding (Camino, 2005; Zeldin, 2004, 2014). Youth-adult partnerships, in a wide variety of settings, are valuable opportunities for youth and adults to work together in a supported, meaningful, and targeted way. As youth with disabilities develop their identities as an advocate, an agent, a partner, and a community activist, youth-adult partnerships provide a framework through which they can establish and achieve both individual and collective goals (Camino, 2005; Zeldin, 2004, 2014).

The literature and past research informed the development of the model below, which outlines how disability oppression is perpetuated by dominant culture, ableism, an inaccessible society, and systemic low expectations. This cycle of oppression results in the marginalization and systematic disempowerment of individuals with disabilities who are denied their basic human rights.
Theoretical Framework: Social Cognitive Theory

The onus of agency. In order for an individual to exercise agency, in accordance with the tenets of Bandura’s social cognitive theory, this person must initiate intentional actions with the explicit goal of exerting energy, effort, and planning to ensure that these actions produce results (Bandura, 2001). This person, an agent, needs to develop their capabilities as a planner, forethinker, motivator, and self-regulator in order to establish and accomplish goals that provide direction and lifelong purpose (Bandura, 2001, p. 8). Most would agree that instilling purpose and meaning in one’s life is quintessential in finding fulfillment. According to Bandura (2001), purpose, meaning, and the pursuit of
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life-satisfaction can be actively sought through establishing personalized goals and authoring a plan to attain them that is adaptable according to personal, cultural, and environmental changes. Bandura acknowledged our highly complex world and both the expected and unexpected challenges that can make navigating life quite difficult (2001, p. 3). The ability of an agent to experience success in achieving their goals is contingent upon their ability to: be aware of capabilities, anticipate potential problems based on context, solve problems creatively according to available resources, size up cultural opportunities and barriers, and after considering these factors regulate personal behavior in order to accomplish goals (Bandura, 2001, p. 3).

For those living with disabilities, being effective agents means not only navigating an array of difficult transitions while problem solving both physical and attitudinal barriers but also being able to cultivate goals in an environment that is plagued by low expectations. The need for agents to not only plan deliberate actions to accomplish intentional goals but also constantly self-examine their own functioning as they strive to make change means that young adults with disabilities need to conceive of themselves as actors in a society that too often bills them as passive recipients of services (Bandura, 2001, p.10). Our cultural disability narrative is quick to define identity, disability, and what constitutes a realistic goal for young adults with disabilities. Thus their ability to practice authentic agency—a task that requires self-awareness, self-reflection, self-regulation, and self-efficacy—is severely limited (Bandura, 2001).

Self-efficacy. Bandura claimed that “efficacy beliefs are the foundation of human agency” (2001, p.10). For agents to be effective they must have a strong sense of self-efficacy, or the belief that they can exert control over their own self (internal factors) and
environmental events (external factors) (Bandura, 2001, p.10). The ability of a person to cause change is inextricably linked to their perception that they have the power to make the desired change a reality. Many young adults with disabilities predict failure when it comes to accomplishing complex tasks in school or pursuing long-term goals like employment. For example, according to Babbit and Burbach (1990), struggling with low self-esteem and lack of confidence has often caused youth with disabilities to experience trouble with vocational pursuits. Babbit and Burbach (1990) also found that although many college students with disabilities hold high career aspirations they do not believe they can actually attain these goals.

Similarly, McCarthy (1986) reported that students with disabilities identified their own personal limitations as their number one impediment to employment (as cited in Enright, Conyers, and Szymanski, 1996). These findings align with Bandura’s research that individuals with low self-efficacy limit their professional and educational options based on perceived shortcomings in their own causality and not their actual performance deficits (Bandura, 1989). While clearly a lack of self-efficacy causes challenges for all individuals, both those with and without disabilities, the ultimate truth remains that “adults with disabilities are less successful in seeking and maintaining employment, achieving a satisfactory standard of living, developing independence, and other quality-of-life indicators than persons without disabilities” (Field, Sarver, and Shaw, 2003, p. 339).

Researchers Scholl and Mooney (2004) analyzed the outcomes of a youth apprenticeship program in Wisconsin to determine how young people with and without disabilities met metrics of success throughout and upon completion of the apprentice
program. In congruence with Bandura’s argument that effective causal agents have a strong perception of their self-efficacy, Scholl and Mooney (2004) found that the youth who had a fortified internal locus of control were more likely to experience success. Equally important to perceiving self-efficacy was the individual’s ability to attribute their success to their own actions. Scholl and Mooney (2004) concluded that if a student believed that they had to rely on adults to make decisions and that they did not have ownership over education and work experiences, the student was more likely to become co-dependent and experience poor transitioning from high school to the adult world.

**Stigma.** Whether an individual is pessimistic or optimistic about their capabilities or whether an individual has self-enhancing or self-hindering thought patterns about their ability to accomplish objectives is largely influenced by their perception of self-efficacy (Bandura, 2001, p. 10). Countless researchers have found that young adults with disabilities experience a pronounced struggle finding success and fulfillment in life. A central attitudinal barrier to consider is how societal stigma and self-stigma influence how youth with disabilities perceive themselves. Stigma is a tool that enables us to categorize qualities, traits, and differences that we deem shameful as attributes that define a specific subset of people. We use this shame to control and police this marginalized group. Stigma also allows us to isolate and disempower these individuals through the use of language that is riddled with negative stereotypes and the construction of false but convenient beliefs that guide our cultural interactions (Byrne, 2000). These manipulations of stigma reinforce and remind stigmatized individuals of their compulsory membership to a subordinate culture (Love, 2015 as cited in Adams et al., 2015, p. 175).

Simultaneously, this bolsters dominant culture’s assertion that the dominant narrative is
the definitive cultural norm. This leaves the stigmatized group feeling disgraced and
discredited by society and members lacking a sense of self-worth (Byrne, 2000).

The pervasive negative stereotypes about disability—whether patronizing
attitudes towards children with special needs or sincere belief that disability renders one
incapable—are often seamlessly internalized. When a young adult with a disability is
exposed to stigma and prejudice it is quite understandable that they may perceive
themselves as inferior and struggle to overcome low expectations. Without exposure to
an alternate narrative that encourages young adults with disabilities to employ self-
reflection to cultivate their own relationship between identity, disability, and their ability
to set and accomplish goals, they will struggle to exercise agency. Bandura (2001)
articulates that “it is partly on the basis of efficacy beliefs that people choose what
challenges to undertake, how much effort to expend in the endeavor, how long to
persevere in the face of obstacles and failures, and whether failures are motivating or
demoralizing” (p. 10).

**Conscientious Reflection, the Narrative Process, and the Importance of Goals**

Quite a few researchers have studied the power of narrative. Two prominent
individuals in the study of self-stories, Wilson and Pennebaker, have divined similar
results indicating that the narrative process serves a fundamentally important purpose of
helping people cope with experiences and make sense of their emotional reactions.
Pennebaker and Seagal (1999) found upon reviewing a series of studies that the narrative
process, even when informally conducted, yielded positive effects including improving
participants’ immune systems, lessening anxiety, helping manage the intensity of chronic
pain, and lowering stress in a variety of situations and settings, i.e. preparing for a job
interview or studying for an important exam (p. 1246). Likewise, Wilson and Dunn (2004) found that individuals who were able to edit their stories on their own terms could explore specific feelings and strengthen their ability to evaluate their own emotional responses (p. 504). In addition, these individuals who had ownership of their stories were also found to be more emotionally accessible while still feeling in control of their emotions (Wilson and Dunn, 2004, p. 504).

Both Pennebaker and Wilson have found that the act of constructing narratives can provide individuals with closure, or as Pennebaker framed it, an “emotional ending” signifying that it is time to move on (Pennebaker and Seagal, 1999, p. 1244). The narrative process can provide closure and give someone the opportunity to come to terms with an experience or event but it also serves as a means to “tie all of the changes in our life into a broad, comprehensive story” (Pennebaker and Seagal, 1999, p. 1250). The power of narrative is not just that it can provide an ending but that it allows an individual to create an organized schematic framework that helps them process experiences, feelings, and beliefs about themselves that can be modified as additional events occur. In this way narrative is about self-awareness, self-reflection, and self-development.

**Goal setting.** Bandura (2001) argued that being a causal agent meant that someone was an active participant in developing their sense of self and modifying the definition of self, which he referred to as “self-renewal,” accordingly when circumstances in life fluctuated and changed (p. 2). He emphasized that individuals needed to be resilient and responsive to life changes that could impact their goal attainment. Being able to evaluate motivation, personal values, and the meaning behind life pursuits ensures that people will work towards their goals or modify their goals to reflect any internal or
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external changes (Bandura, 2001, p. 10). Bandura (2001) stated that this cognitive process, which he referred to as conscientious reflection, was a means through which the individual could both understand their goals and author a plan to secure these goals. Bandura argued that goals reflect more than just instinctual desires; they are also manifestations of our core values which in turn shape how we see ourselves and how we want others to see us (2001).

Having goals makes our actions and activities purposeful and meaningful but it also gives our personal identities substance (Bandura, 2001, p. 8). The concept of conscientious reflection was critical in Bandura’s social cognitive theory because engaging in this process made “life personally manageable but worth living,” meaning individuals could exercise agency due to strong perceptions of self-efficacy (2001, p. 3). Through conscientious reflection, individuals can evaluate how they live their lives and in turn this reinforces a self-identity that guides their approach to establishing goals, achieving goals, and coping with perceptions of self-efficacy and agency, which can either hinder their performance or enhance it (Bandura, 2001, p. 3). As this dissertation in practice has discussed, many young adults with disabilities struggle in important life domains, especially during the transitional period from young adulthood to adulthood. Bandura (1989) argued that for members of marginalized groups, social influences like stereotypes, stigma, and diminished expectations for achievement were incredibly damaging and negatively impacted self-efficacy beliefs, self-esteem, and level of self-worth (p. 1179). Ultimately if young adults with disabilities do not think anyone believes in their potential, why should they? This lack of faith in the self leads to stunted goals and
a propensity to admit defeat sooner, attribute a small bump as a sign of failure, and give up instead of problem solve (Bandura, 1989).

In addition, these negative experiences tend to stick with the individual longer so their “recovery” process, acknowledging their resiliency and capacity for agency, takes a significantly longer period of time (Bandura, 1989). In other words, these individuals have a harder time bouncing back and an even harder time trying again. This often results in the individual lowering personal expectations and believing that others have done so as well. This unquestionably contributes to our culture that sees disability as a sign of inability and dependence.

**Goal attainment.** When researchers Getzel and Thoma (2008) worked with college students with disabilities to better understand why some have successful outcomes and others do not, they found that college students with disabilities who are self-aware, confident in making important decisions about their goals, flexible learners, and have developed a personalized relationship with their disability are significantly more likely to be successful in college. However, the process of translating advocacy, agency, activism, and disability-identity into personally relevant, useable definitions is quite complex. In addition, we do not live in a vacuum so youth must also translate this information in relation to their ever-changing environment. This means interacting with a multitude of service systems, processing stigma, stereotypes, and artifacts of ableism, and working independently and interpedently to accomplish goals.

Navigating life transitions means writing your own story, a story that helps you learn from your mistakes and organize your own goals, and also directs you down your desired path. This requires an understanding of the self while simultaneously nurturing a
loud and authentic voice that expresses your changing needs as your goals and environment change. In alignment with the theories and research of Bandura, Wilson, and Pennebaker, I contend that through conscientious reflection we can conceive of ourselves as agents and through narration we can edit our self-stories to redefine our effectiveness as agents.

Our understanding of the disability story will only change when we let those who live it, narrate it. The power of narrative is that it creates stories, points of conversation, and serves as a vehicle for differing perspectives. Through narrative we not only shape our own lives but can better work together as neighbors, partners, coworkers, and professionals because it suggests possibilities for us all living together (Mitchell and Snyder, 2015 as cited in Adams et al., 2015, p. 126). As eloquently stated by Mitchell and Snyder (2015), “the understanding of narrative plays a crucial role in how we imagine social worlds” (as cited in Adams et al., 2015, p. 126). I argue that engaging young adults with disabilities in a disability-positive environment will lead to a reformed understanding of agency. Disability-positive environments are youth-adult partnerships that incorporate goal setting and reflection in order to facilitate authoring an authentic narrative on identity, disability, and agency. Identity, disability, and agency are three fundamentally important elements that influence the balance between struggle and success.

Young people with disabilities need their own disability language, a language that not only shapes a positive self-image but also empowers young adults to work effectively with adult partners. Youth-adult partnerships link youth to adult partners who are willing and prepared to provide interpersonal guidance as well as learn from and work with youth
on a critical community issue (Camino, 2005; Zeldin, 2004, 2014). My concept of
disability-positive environments combines productive partnerships between youth and
adults, conscientious reflection, and disability competencies into a safe space for youth to
invest in self-exploration. Disability-positive environments have the potential to help
young adults with disabilities not only develop as true self-advocates and agents, but also
self-assured activists for social justice.

Advocacy and Activism: Bettering the Self and Improving the World

Understanding advocacy. In order to practice effective advocacy an individual
must understand what they need and have the ability to communicate those needs to
individuals, institutions, and systems. By definition advocacy involves requesting
services or resources, supporting a cause, and espousing the principles of the cause
you’re advocating for (Dictionary.com, n.d.). Effective advocacy results in attaining
requested services and resources as well as enlisting others in your cause. Thus for youth
with disabilities the practice of effective advocacy hinges on developing a positive
disability identity. Self-advocates need to have the competence and confidence to
translate their needs into a language that dominant culture recognizes and responds to.
Generalizing this narrative so it is applicable to a variety of systems like educational
institutions, employment settings, and health care services maximizes the likelihood that
a young adult with a disability will acquire accommodations, set a healthy expectation
level, and experience success.

In an effort to amend our cultural tendency to silo minority groups, creating cross-
diversity opportunities where individuals can commune with others who share a history
of fighting for social justice can strengthen how marginalized communities partner in
advocacy, activism, and leadership efforts. Finally, prioritizing opportunities for youth with disabilities to participate in youth-adult partnerships is of utmost importance as these relationships empower and prepare young people to develop into responsible citizens, professionals, and activists. These elements culminate, as defined in this dissertation of practice, into a disability-positive environment. A disability-positive environment is a program that incorporates identity and advocacy development, offers opportunities for cross-disability and cross-diversity engagement, and provides a schematic framework for a functional youth-adult partnership.

In order to address the needs of all types of people while creating a society in which everyone has access, we must redesign our framework. We need to change how we think and talk about disability, diversity, difference, subordinate groups, targeted identities, neurodivergence, sameness, homogeneity, normalcy, able-bodiedness, dominant culture, or any other words we use to reinforce our divisive culture that has a historical habit of systematic oppression. We need to embrace the beautiful differences and unique experiences of all people as these expressions of diversity add richness to our cultural mosaic. It is important to honor the identities of individuals but we need to stop using identifiers as a way to marginalize, restrict, and disempower an entire subordinate community. We should not perpetuate stigma and fuel stereotypes. Safeguarding civil rights for all of our citizens should be at the top of our national leadership agenda.

**Applying activism.** As defined by Barnes and Mercer (2010, p. 176), disability activism refers to “collective political action by and for people with disabilities” with the primary objective of empowering the disability community to use their influential voice and their intentional actions to determine their position in political, social, and cultural
spheres (Longmore, 2003, p. 231). Self-advocacy is a fundamental skill that individuals with disabilities must master in order to successfully navigate their own environments as well as a skill that must be employed effectively when it comes to impacting the larger community, like through policy changes. Nepveux (2015 as cited in Adams et al., 2015, p. 21) notes that while advocating on behalf of others, an extension of self-advocacy, can be defined as activism, the practice of meaningful disability activism requires that individuals with disabilities demonstrate collective autonomy through leadership. Examples of collective autonomy and activism can take on many forms. Whether they are political protests, performances, disruptive occupations, or any other manifestation of a movement, their primary purpose is to: make every day aspects of ableism visible, protest unjust political policies and societal norms, propose new disability-positive policies, counter prejudicial media and portrayals of disability, and cast a spot light on disability experience and disability culture that has developed in the context of dominant culture’s landscape (Nepveux, 2015 as cited in Adams et al., 2015, p. 25).

Understanding why a law should be challenged, why all curbs should have curb cuts, and how stigma and prejudicial language are damaging is another critical byproduct of activism. As injustices and inequities such as these are scrutinized, visible displays of activism, like rallies and protests, play a key role in bringing the “disabled” into the able-bodied world as active interrupters in daily life. However advocacy is an incredibly integral force when it comes to building accountability mechanisms to ensure sustainable changes even though it is often a less visible means of enacting change. Advocates reform the system from within as activists publically maneuver through an able-bodied, neurotypical world to bring disability to the forefront of cultural consciousness.
Explaining the need for change through narratives, personal accounts, and visible
displays of activism and agency help redefine a marginalized identity, like that of “being
disabled.” This exchange personifies an identity, makes the situation much more
relatable, and this elicits compassion in regard to issues faced by the community. In order
to commemorate, learn from, and continue the push towards progress, the disability
community must preserve the accounts, stories, wisdom, and experiences of disability
activists as well as advocates (Nepveux, 2015 as cited in Adams et al., 2015, p. 24).
Capturing these stories, triumphs, and exemplary demonstrations of activism through
interviews, memoirs, blogs, zines, photographs, films, etc., is essential so these legacies
of leadership will inform future action—the cultivation of a shared disability history. As
disability leaders author their own disability narratives, document their own disability
experiences and perspectives on history, and frame their own approach to accomplishing
goals, they challenge our ableist narrative of disability.

**The Significance of Youth-Adult Partnerships**

Youth-adult partnerships (YAPs) provide young people an opportunity to develop
skills, broaden attitudinal horizons, practice articulating their ideas and exercising
advocacy, and explore opportunities for activism regarding matters of social justice
(Camino, 2005; Zeldin, 2004, 2014). Inviting young people to enter such pivotal
partnerships also provides a valuable opportunity for adults to challenge their beliefs,
learn from different perspectives, and usher in a new cohort of future leaders (Camino,
2005; Zeldin, 2004, 2014). In this way YAPs foster the development of an effective
citizenry and create a nation with structures, institutions, systems, and an ideological
framework that ensures “young people’s developmental needs are met, services reflect

When youth with disabilities have opportunities to share relevant experiences, knowledge, and insight with a diverse group of influential stakeholders this results in the expectation that both youth and adults have the power to produce collective action (Call et al. 2002; Ginwright et al. 2006; Linds et al. 2010 as cited in Zeldin et al. 2014, p. 338). Ultimately the most effective method of incorporating young people into appropriate decision-making and idea sharing is through YAPs, which have the “explicit expectation that youth and adults will collaborate in all aspects of group decision-making from visioning, to program planning, to evaluation and continuous improvement” (Zeldin et al. 2014, p. 338). However, creating a climate that embraces meaningful youth engagement in a functional way takes effort, energy, resources, and purposeful instruction.

**Ensuring program fidelity.** Not all governments, corporations, agencies, and community coalitions are equipped with the knowledge or tools to implement a proper YAP. YAPs are not packaged interventions that can easily be replicated, implemented, and sustain their quality (Zeldin et al. 2014, p. 345). While there is no specific “YAP formula,” there are certain integral elements that nurture the development of a robust and responsible partnership. In order to optimize the true potential of a YAP the relationship must incorporate inclusive decision-making, mutuality in teaching, learning, and reflecting amongst youth and adults (Camino, 2005; Kirshner, 2007; Mitra, 2008; National League of Cities, 2010; Yates and Youniss, 1996, as cited in Zeldin et al. 2014). Understandingly, building healthy YAP programs is a somewhat complicated endeavor in
part because recruiting and engaging youth can be difficult. In fact many YAP programs have experienced decreases in quality relationships and quality products because adults do not have the right skill set to work with young adults (Camino, 2005). Other programs have suffered because the cultural climate in which the YAP is situated grapples with societal norms, expectations, and policies that cannot authentically support a YAP in its truest form (Zeldin et al. 2014). In addition since the study of how we conceptualize and utilize YAPs has only begun relatively recently, we are still lacking methodology and assessment protocols to truly measure effectiveness and outcomes (Zeldin et al. 2014).

**Common pitfalls.** The novelty and appeal of YAPs has bred a surge of programs that, while they may have good intentions, do not fully coalesce the principle elements of a YAP into a sound, applicable program. Camino (2005) found that there are three basic pitfalls that undermine the effectiveness of a YAP. The first pitfall is the assumption that youth partners should do everything of importance. The belief that youth will benefit from experiencing as many opportunities as possible and taking on as many responsibilities as possible has led adult partners to take too many steps back. While adults may voice their confidence in youth ability and strive to optimize their learning experience the reality is that not all young people have the skills or desire to accomplish every task in a YAP. Camino (2005) cites how many youth join YAPs because they seek “coaching, guidance, modeling of behaviors, and sharing tasks” from and with experienced adults (p. 77). YAPs foster phenomenal collaborative learning environments but the integrity of these programs requires responsibility and ownership on all sides. If only youth or only adults are shouldering the bulk of the program’s responsibility there is an increased likelihood that the quality of the program will decline.
Without employing a true corroborative experience, a YAP completely misses the mark. YAPs demand that resources, connections, experiences, and knowledge are exchanged meaningfully between partners (Camino, 2005). Valuing each partner’s contributions is critical in a YAP. However another noted pitfall in the YAP process is the belief that adults should “give up power” and “get out of the way” so young adults can take center stage (Camino, 2005, p. 77). This flawed logic frames power as a commodity and thus in order for youth to gain power adults need to relinquish power. However power is not part of a zero-sum equation. The equitable distribution of responsibility and power is a critical element in creating and sustaining a YAP. The last problematic pitfall experienced in YAPs is the tendency to place youth on a pedestal. The attitude that youth bring all of the “energy, vibrancy, and authenticity” to a program implies that adults are not co-learners or equal contributors (Camino, 2005, p. 79). In the same vein, YAPs that concentrate on adult experiences more than youth experiences indicate that adult partners have more valuable experience. In fully actualized YAPs both adults and youth provide meaningful substance and useful contributions. Therefore in order to ensure YAPs' functionality and effectiveness, both youth and adults need ongoing instruction to better recognize, utilize, and be realistic regarding each other’s contributions.

**Strengthening YAPs through reflection.** Trainings, opportunities for development, and other interventions to overcome potential pitfalls need to be applied so that YAPs remain trusted and constructive programs. One such worthwhile practice is providing time for reflection during YAP meetings and activities (Camino, 2005). Freire (1983) wrote of the need for “critical literacy,” which he argued would enable people to
change the conditions of their lives (as cited in Camino, 2005, p. 80). According to Freire, someone with advanced critical literacy could accurately assess the condition of their life and place environmental situations, like common events and daily difficulties, into a broader context of community, policy, and social forces.

In Bandura’s words, through dedicated reflection we can have a better understanding of who we are, what we need, and how to make decisions and take action to accomplish our goals. Bandura’s construct of conscientious reflection outlined the necessary steps of processing past, present, and future events, perceiving the self as an agent, and understanding cultural and environmental context in order to achieve goals and lead an independent, meaningful life. In this way YAPs designed with ample time for conscientious reflection provide a worthwhile opportunity for youth to develop skills regarding reflecting on the self, personal goals, the goals of the program, and how to align bettering the self with improving a larger organization.

When YAPs serve as learning communities where individuals can “reflect, dialogue, and learn together” (Camino, 2005, p. 80) youth and adult leaders have a space where they can build networks, expand resources, share information, and problem solve. By challenging current practices and discussing solutions together, YAPs form environments where true innovation and collaboration can yield actual results. Valid YAPs require adults to practice “guided participation” in which adult partners “guide, scaffold, and incentivize the learning and reflection of youth” while responding to shifting group dynamics between the program, participants, and policies (Zeldin et al. 2014, p. 345). When both youth and adults can reflect on not just the progress of the program but also their own individual level of engagement in the YAP, it refines their
capacity as an agent.

**Shared vision and joint decision-making.** It is paramount to keep in mind that YAPs connect youth and adults so they can learn together, which inevitably means there are growing pains and educational lessons along the way. Camino (2005) argues that a pivotal practice in fostering the fruitful harmony of a YAP is articulating the logic behind the program. This includes defining why the program exists, outlining the mission, listing desired goals and objectives, etc. Ultimately in order to keep YAPs on track, ensure productivity, and promote a healthy work environment there must be a consensus amongst stakeholders regarding the primary purpose of the YAP. It is imperative that both youth and adult partners have clear roles and expectations, which situate their position and responsibilities in relation to the other partners. This ensures that every member of the team has a recognized, purposeful place within the YAP (Camino, 2005, p. 76). YAPs need to engage youth and adults in a meaningful way that champions the mutuality of teaching and learning as well as the mutuality in decision-making. Zeldin et al. (2014) state that when adults are willing and able to share power while providing scaffolding, mentoring, and direct instruction to youth, youth are more likely to believe they can influence decision-making since they are trusted leaders and learners (p. 338).

Another key piece of constructing a functional YAP is emphasizing community change. When adults state that a YAP's purpose is explicitly to develop leadership skills for young people, the partnership is usually not as strong or sustainable (Camino, 2005). The most steadfast, creative, passionate, and productive YAPs involve youth and adults collaborating to address “community problems, and build healthier, more livable environments for the common good” (Camino, 2005, p. 82). While individual
development is of course important for both youth and adult partners, Camino (2005) and Zeldin et al. (2014) argue that this skill set is best conceptualized as part of the hidden curriculum. The main purpose of the partnership is working collectively towards a shared vision that benefits the larger community.

**Fostering citizenry.** Responsible development and utilization of youth-adult partnerships has the potential to sponsor a generation of youth who use their voice to improve their own situation and serve their communities. The ability for a young person to self-advocate and act in the best interests of others “is an important precursor to competence, identity formation, and social trust” (Arnett, 2002; Flanagan, et al. 2010; Peterson, 2000; as cited in Zeldin et al. 2014). Research links youth participation with “the development of agency, empowerment, and community connections” (Christens and Peterson, 2012; Evans, 2007; Krauss et al. 2013; Larson and Angus, 2011; Mitra 2004; Zeldin, 2004; Zimmerman et al. 1999 as cited in Zeldin et al. 2014, p.337). Ultimately young people involved with youth-adult partnerships have higher levels of empowerment and increased capacities for agency (Zeldin et al. 2014). YAPs provide youth with a safe space to practice targeted critical thinking skills and pursue collective action with the support of peers and adults. In addition YAPs also present youth partners with opportunities to practice communication skills with peers, adults, and program stakeholders, as well as develop their own critical literacy competencies.

**Inception of Disability-Positive Environments**

Based on the literature and related research, it is well founded that reflection is a key element of personal growth. For youth with disabilities, improving self-awareness, self-regulation, self-determination, and self-efficacy results in being a more confident
problem-solver, authentic learner, and efficacious agent. Through the process of reflection, an individual is afforded the opportunity to author a narrative featuring the self as agent, advocate, and activist who can make individual and community improvements. Disability-positive environments integrate the schematic structure of YAPs with conscientious reflection in a context that supports the specific needs of young adults with disabilities. In this safe, dedicated space, youth collaborate on individual and group goals, practice self-renewal to hone a positive disability-identity, and challenge our ableist narrative with their success stories. Within the framework of high expectations and individualized supports youth empowerment and youth leadership are possible.

I believe that YWD who have participated in disability-positive environments are more likely to be skilled agents, advocates, and activists who can challenge the negative stereotypes and low expectations of ableism. In Pittsburgh, PA, there are a multitude of YAP-modeled programs for youth with disabilities that pledge to engage “youth to develop and deliver trainings, author media and communications initiatives, and evaluate policies with an intergenerational team” (Zeldin et al. 2014, p. 338). Adaptive sports programs, social and recreational groups, advisory boards built to address healthcare issues, etc. are all potential disability-positive environments that aim to form a learning community (Senge, 1990), a community of inquiry (Friedman, 2000), or a reflective practicum (Schon, 1987), where YWD can learn about themselves, from peers, and adult partners. Advocacy programs for YWD in Pittsburgh, PA, strive to support youth and young adults as they practice self-advocacy, define their disability-identity, reflect on their goals and how to accomplish them, and practice living as agents who can make meaningful changes. However whether or not these programs comprehensively provide
this experience or contribute to positive post-high school outcomes for YWD requires further study.

**Supporting Agency through Authentic Learning**

In order for disability-positive environments to be meaningful and applicable to everyday life, they must provide opportunities for authentic learning. Land, Hannafin, and Oliver’s (2012) research on student-centered learning environments established four core values of successful environments that nurture authentic learning. These core principles call for students to: have access to multiple perspectives, resources, and representations; define their own learning; incorporate prior and everyday experiences in meaning construction; and participate in authentic tasks and sociocultural practices with appropriate scaffolding (p.8). Therefore, in order for authentic learning to take place a disability-positive environment must not only satisfy the four criteria for successful student-centered learning environments, but also foster an opportunity for youth leaders to encounter new information, reflect and make sense of this content, and critically challenge this information by asking questions and seeking additional clarifying resources. Ultimately the learning process broadens horizons, encourages youth leaders to find new experiences, and expands their capacity for empathy. It is imperative that such environments are also equipped accordingly to meet the developmental, emotional, and learning needs of youth with disabilities.

**Multiple perspectives, resources, and representations.** In effective disability-positive environments youth are exposed to a diverse group of individuals; they are cross-disability, support intergenerational partnerships, include youth from a variety of backgrounds, possess different worldviews, etc. The unifying principle is a commitment
to work together in order to fulfill the mission of the program, which necessitates organized teamwork. Actively participating in a disability-positive environment lends to the reciprocal sharing of perspectives, experiences, and talents. However in order to fully maximize investment, group members must listen to and learn from each other. Youth leaders must mature as critical thinkers and analytical listeners, and practice critical literacy skills so new information can be assimilated and accommodated into their personalized contextual schematic frameworks. Ultimately youth leaders must have the ability to make their own educated decisions while being cognizant and respectful members of a team.

**Self-directed learning.** Land, Hannafin, and Oliver’s (2012) student-centered learning environment values reinforce that disability-positive environments must operate as platforms for youth to develop competencies as self-directed, deductive, socio-political beings to empower and prepare these learners for a future of smart goal-setting and effective decision-making. Ideally, disability-positive environments nurture a healthy student-centered learning environment with their organizational structure, youth-directed learning objectives, level of individualized support for both youth and adults, semi-guided opportunities for goal-setting, and their overall approach for facilitating teamwork between partners and community stakeholders. Under these conditions youth leaders with disabilities will be able to explore their own identities as learners and confidently tackle new and rewarding experiences.

**Generalizable skillsets.** Youth need to be able to generalize their skills in a variety of contexts, environments, and problems. The relevance and usefulness of our learning can be summed by the adaptability and fluidity of our skill set, schema, and
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overall ability to expand our knowledge base. Agents are able to effectively assess themselves, evaluate their environment, request supports, and apply accommodations in order to achieve goals. The ease with which a youth transfers what they’ve learned into intentional actions contributes to their capability and confidence as decision makers, learners, and leaders.

**Sociocultural practices.** Learning is deeply embedded in societal values, cultural context, and personal experiences. While past cognitive theories maintained that individuals were independent thinkers with isolated minds, according to situative theory learning is socially and culturally constructed (Barab and Duffy, 2012). Situative theories explore how interactions with the world produce social understanding and simultaneously an understanding of the self. Land, Hannafin, and Oliver (2012) referred to this in their descriptions of authentic learners as being sociocultural, sociopolitical beings. In order for learners to truly understand a concept they have to frame the concept using the structure and terminology of their own schematic framework.

**Social Cognitive Theory and Authentic Learning**

As Bandura (1989, 2001) articulated in his social cognitive theory, being able to reflect, frame, and apply information to the self and the self’s specific environment is imperative in order to evolve as an independent and purposeful person. Through the construction of an identity that considers the boundaries of the external environment, establishes personally meaningful goals, and learns how to achieve these goals, one builds an internalized sense of self that directs understanding and action. Bandura’s research and the wealth of information generated in the field of disability studies support the finding that how youth with disabilities interpret the self and their external
environment impacts their overall ability to practice agency. For example, many youth with disabilities interpret the external environment as defeating and this contributes to their perception of themselves as incapable of making positive changes in their own life. This negative external and internal lens can result in an inefficacious identity or, in other words, an agent with low expectations and diluted goals.

As mentioned earlier, Land, Hannafin, Oliver (2012), Bandura (2001), and Barab and Duffy (2012) emphasize that the process of authentic learning is embedded within the larger context of our social world. Learners must practice solving problems that affect themselves, their peers, their family members, and people in their community. Barab and Duffy (2012) contend that learners need to have community experiences in order to solve community problems. Involvement in a community context also helps a student shape their sense of self as learning is no longer about catering purely to individual needs but practicing problem solving in order to better the community. Again in reference to the power of authentic learning, knowledge that is applicable and relevant to everyday life is substantially more meaningful. Practicing problem solving, like in a disability-positive environment, is highly beneficial for youth with disabilities as it enables them to become more effective at transferring various skills, like self-advocacy strategies, to real-world situations. In other words, analytical thinking is translated into informed acting.

When critical thinking and reflecting are valued components of the problem-solving process, individuals increase their capacity to anticipate future problems and thus can act proactively. The ability to transform from a reactive to a proactive problem-solver is an integral objective in Bandura’s conscientious reflection process. Ultimately, learning connects you to your environment and gives you a frame of reference for self-
identity. Your values and priorities, which are mirrored in the goals you set, are also a reflection of how you see yourself (Bandura, 2001). How you define yourself as a self-advocate extends to how you perceive your capacity for agency as a member of your community. The development of these identities coupled with the reflection process can potentially enrich your schematic understanding of self-efficacy. How you interpret your abilities as a self-advocate and your level of efficacy as an agent can influence the amount of responsibility you assume as an activist (Zeldin et al. 2014).

**Practicing Leadership in a Neurotypical, Able-bodied World**

**Societal expectations of leadership.** Analyzing the language and ideas we use to shape programs for YWD is critical in order to better understand our attitudinal assumptions and societal priorities. This enables us to ascertain what we value when working with the disability population. It is important to be aware of what resources, programs, and services we offer YWD as well as what expectations we set for them, and how this compares and contrasts to the concrete skills we think young adults with disabilities need in order to lead their own lives. In order to glean the primary focus of a breadth of studies on disability, Johnson (1999) conducted a semantic analysis looking for the most frequently occurring terms, definitions, and themes in the work. Johnson uncovered that the most prevalent themes within the work were self-determination, self-advocacy, empowerment and power, and leadership, which could be further categorized as “disability leadership” and “generic leadership.” Johnson then explored how these terms were framed by the authors; did these disability constructs concentrate on the individual making internal changes or did the authors dedicate more energy on exploring the impact individuals can have on their external environment?
Evaluating language. According to the literature, Johnson found that the majority of researchers defined self-advocacy and self-determination as revolving around satisfying individual needs and developing individual skills. In order to increase one’s capacity for self-advocacy and self-determination the literature cited that one must gain more power. Power was primarily defined as having access to resources, particularly financial resources. Having monetary resources facilitated the process of accumulating additional power and acquiring even more wealth. This is a clearly logical rationale considering our hyper capitalist culture. For all members of marginalized communities, accumulating wealth, while it would not liberate you from your membership to a targeted group, would exponentially improve your situation. The field of disability studies has yielded findings that individuals with disabilities who had financial stability or came from wealthy families had more opportunities to make decisions, experience independence, and maintain a better quality of life. These authors also framed self-advocacy and self-determination as ways to practice leadership. In sum, opportunities to gain authority, leadership, and control are more likely to be arbitrated when youth with disabilities have both financial power and agentic empowerment.

Generic leadership and disability leadership. Johnson (1999) found that while all the authors used the word “leadership” they actually were employing two distinct definitions of leadership that highlighted our different expectations for youth with disabilities. Johnson defined these varying definitions of leadership as, “generic leadership” and “disability leadership.” Generic leadership involves addressing community or collective needs. Practicing effective generic leadership requires the ability to enlist followers to act in order to obtain goals desired by the majority. Effective leaders
are persuasive, confident, and determined when making decisions and actively demonstrating their leadership. “Generic leadership” requires a leader to not only have followers but also have the competency to achieve a common goal and ideally bring about social change (Johnson, 1999, p. 14). Thus, generic leaders are not only capable self-advocates but accomplished community leaders who can operate effectively in their external environment.

In contrast, “disability leadership” revolves primarily around the development of self-advocacy skills and praising youth with disabilities for accomplishing tasks relegated to the status of the self. Johnson (1999) stated that the fact we use “self-advocacy” and “leadership” interchangeably when conceptualizing goals for youth with disabilities reveals a “very limited view of the potential leadership of people with disabilities” (p. 13). Thus under the parameters of “disability leadership,” youth with disabilities are “leaders” when they practice self-advocacy and self-determination. In addition, Johnson found that literature utilizing the “disability leadership” definition of leadership included less discussion on the need for youth to expand agentic capacities or participate in community activism.

**Understanding attitudinal assumptions.** Johnson’s (1999) thematic analysis of “generic leadership,” exacting external changes, and “disability leadership,” forging internal modifications, examines our cultural preoccupation with teaching youth with disabilities to focus mainly on caring for the self. This also reflects our “leadership” expectations for youth with disabilities and their peers without disabilities. As mentioned above, Johnson argued that we too commonly author two definitions of leadership with very different criteria and expectations. We have drafted distinct definitions of leadership
because we do not perceive individuals with disabilities as capable of actually practicing “generic leadership” or able-bodied, neurotypical leadership. If an individual with a disability is able to practice “generic leadership” they are regarded as “inspirational.” Individual evolutions of leadership should not be a process reserved for able-bodied, neurotypical people.

When equipped with supports, resources, and opportunities we can all aspire to make our world a better place. Ableism forecasts that our young adults with disabilities will continually struggle to realize their capacity as true leaders, activists, and generators of change. For leaders with disabilities we expect less success and less agency because disability implies inferiority. Ultimately these diminished expectations tell our youth that “disability leaders” are inherently not as qualified as their able-bodied, neurotypical counterparts.

Kouzes and Posner (1995 as cited in Johnson, 1999) define the central qualities of leadership as innovation, change, and new ideas. Our youth with disabilities need to be problem-solvers and decision makers in all aspects and all spheres of life. Our educational efforts must support the reality that these youth have potential and they have power. While the expression of self-advocacy and agency will most definitely reflect an individual’s strengths, needs, and learning path at that point in time, an appropriately tiered support system can empower individualized practices of leadership. Johnson ended their assessment stating that when advocacy is used as a means to achieving social change this signifies the practice of leadership (1999, p. 12). Thus in disability-positive environments where youth are encouraged to become active community contributors, passionate and knowledgeable activists, and learning leaders, the constructs of self-
advocacy and leadership must incorporate an expanded definition that explores the self as both an agent of personal change and an activist for community progress.

**Leadership and the Social Model of Disability**

**Physical adaptations.** Making measurable progress regarding any social justice issue requires incremental changes that ideally build momentum and ultimately result in positive cultural shifts. In the field of disability studies the desired ideological shift is the adoption of the social model of disability. This in turn would manifest as the real world implementation of the model of universal design, or inclusive design as it is known in Europe (Cogdell, 2015 as cited in Adams et al., 2015, p. 60). Universal design, which is often situated within the field of education, states that the physical world and the learning world need to be accessible to individuals of all abilities (Johnson and Pliner, 2004). As a matter of social equity, sustainability, and financial responsibility, Cogdell (2015 as cited in Adams et al., 2015) and Braungart and McDonough (2001) argue that engineers and designers can best serve humanity by integrating inclusive design from the outset. We can maximize the usability of products, spaces, and services if they are designed to be responsive and malleable to the naturally fluctuating range of abilities that people possess over time (Cogdell, 2015 as cited in Adams et al., 2015, p. 59). Cogdell concludes that designing for people of all capabilities not only respects human dignity but also affirms human rights and ensures access (2015 as cited in Adams et al., 2015, p. 60).

The social model of disability argues that merely modifying our physical space, like putting curb cuts into sidewalks, or the ad hoc delivery of accessible products, is not sufficient. There needs to be a systematic change not only in how we design our products, build our physical institutions, or teach our youth, but how we perceive disability. In
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isolation, accessible opportunities and resources will not lead to the adoption of a large-scale sustainable disability framework that replaces the constraints of ableism. Culturally we need to prioritize amending inaccessible institutional and systemic structures and services so everyday barriers are neither physical nor attitudinal.

Attitudinal shift. Why do we aim to “fix” or augment people with disabilities when we can adjust and adapt our institutions, systems, and landscapes to be universally accessible? My introduction, entitled “Society of Staircases,” uses the physical structure of staircases to epitomize our culture of privileged accessibility. This metaphor explores both how we keep building physical structures that target and hinder people with disabilities who cannot use them, requiring them to find another way to access the same space as able-bodied people, and how dominant culture is quite comfortable operating under the parameters of ableism. “Stairs” and their many manifestations send the message that individuals with disabilities do not fit in our world. This message amplifies our cultural narrative of exclusion as we opt to build barriers for people with disabilities than inconvenience neurotypical minds and able bodies.

Culturally we operate under the astoundingly incorrect assumption that disability is predictable, but disability is not a static condition. As stated by Cogdell, “disability is an ever-present human condition, an integral part of the continuum of every individual’s life” (2015 as cited in Adams et al., 2015, p. 59). Our cultural definition of disability is intricately intertwined in the ability to access everyday elements of life. Since our current world values and replicates neurotypical, able-bodied structures and systems, when old age, illness, and the natural process of becoming dependent emerge, this simultaneous lack of access labels individuals as “disabled.” This label designates membership to the
largest minority group in the United States (Adams et al., 2015) as there are nearly 40 million people living with disabilities (Stevens, Carroll, Courtney-Long, Zhang, Sloan, Griffin-Blake, and Peacock, 2016). In fact, approximately 10 percent of the world’s population—or 650 million people—live with a disability (Adams et al., 2013. Ableism maintains that disability is inherent inferiority but in reality disability is a social construct that is governed by the ability to access opportunities and autonomously improve quality of life.

Challenging ableism and advancing the status quo to benefit the majority of individuals is a matter of social justice. We must challenge how we define disability by expanding our principles, practices, and platforms to increase access and justly practice inclusion. The marriage of critically thinking about disability and engaging in activism can result in individual, institutional, and systemic changes that embrace the true spectrum of the human condition. Primary partners in this work are youth with disabilities who deserve opportunities to author their own narratives and forge agentic leadership skills. Disability-positive environments provide an optimal space for youth with disabilities to grow as advocates, agents, and leaders who can exact ownership of their goals, decision-making, learning trajectories, and accomplishments. These environments foster skill building and support youth with disabilities as they explore their self-efficacy within a culturally competent and inclusive framework. Through authentic learning and high expectations, disability-positive environments encourage youth with disabilities to conscientiously reflect on how they think about disability and how they can actively improve access for individuals of all abilities.
Disability Advocacy in Pittsburgh, PA: Context Review

In disability studies, examining access as a privilege, right, and predictor of success is essential. We all have inalienable rights when it comes to exercising political choice, having financial autonomy, being safe and healthy, and forming relationships as social beings. In order to truly engage and interact in society, individuals of all abilities need access, from entering buildings, using public transportation, getting an education, finding employment, receiving adequate healthcare, to navigating other aspects of daily life. According to the social and biocultural model of disability, disability becomes a limiting condition when there is restricted individual, institutional, and systemic access. Unbalanced access to everyday life for individuals with disabilities fuels poor outcomes for the disability community and the perpetuation of our ableist narrative.

We live in an ableist world because we have designed a culture where the bodies that have the best chance of being actualized citizens are able bodies with neurotypical minds. This means that in order for individuals with disabilities to be effective citizens they need accommodations to experience the same access to everyday life that is experienced by their non-disabled peers sans accommodations. However, accommodations are sometimes superficial supplements that when implemented incorrectly can negatively impact expectations for the disability community and thus inadvertently perpetuate ableist stigma. In this regard, challenging ableism is a battle of changing our cultural ideological framework of disability. Cycles of oppression are continuously reinforced when left unquestioned and not dismantled by advocacy, activism, and attitudinal shifts. Thus individuals with disabilities must develop a better
capacity for agency to enable them to reclaim opportunities, experiences, and thus increase their access in their community and city.

Empowering young people to build a more functional relationship with disability is a matter of social justice. Individuals with disabilities need to be respected and acknowledged as equal citizens and thus be granted full access and inclusion in everyday society. This means access to educational opportunities, gainful employment, sufficient health care, economic freedom, political participation, and forging social relationships as effective agents, advocates, activists, and leaders. Disability advocacy in Pittsburgh, PA has a long and rich tradition of personal empowerment and cross-system, cross-agency partnerships. Local government entities, non-profit organizations, education and medical systems, parents, and advocates have worked together to improve access and increase opportunities for the disability community via a wide continuum of initiatives and projects. My designed and defined disability-positive environment borrows its constructive characteristics from many of these existing programs but seeks to add other advantageous qualities to create improved systems.

Due to the struggles associated with creating and maintaining functional youth-adult partnerships, honoring and amplifying youth voices in a quickly changing world, and supporting young people and their families in the fight for full societal access, many programs understandably fall short. These programs, recreational opportunities, and skill-building groups are often lacking in regard to how they intentionally and effectively empower youth as competent and capable agents. I believe that youth with disabilities who have participated in disability-positive environments are more likely to be skilled agents, advocates, activists, and leaders who can challenge the negative stereotypes and
low expectations of ableism. I posit that creating disability-positive environments by improving existing disability advocacy programs will both target and improve the efforts of an already promising advocacy network in Pittsburgh, PA.

The disability community in Pittsburgh has a healthy history of advocacy, activism, engaging diverse stakeholders, and spawning long lasting partnerships between individual advocates, agencies, and government offices. Likewise, since the early 1960s, the city of Pittsburgh has framed inclusion and access as priorities for expansion. This commitment to creating a community that supports diverse needs has led to the birth of progressive practices and innovative variations on service delivery. For example in 1968 Mayor Richard Caligiuri formed the Committee on Architectural Barriers in response to the passage of the federal Architectural Barriers Act of 1968 (FISA Foundation, 2015). This act mandated that federally funded buildings be made accessible and Caligiuri’s committee strived to implement a construction plan that aligned with the priorities of the disability community (FISA Foundation, 2015). Incorporating stakeholder voices was a practice also utilized in 1978 when the Port Authority of Allegheny County created the Committee for Accessible Transportation. This committee brought together county employees, private transportation providers, Carnegie Mellon University researchers, and individuals with disabilities to address transportation gaps (FISA Foundation, 2015). The following year the Committee for Accessible Transportation launched ACCESS, an innovative shared-ride system for individuals with disabilities, which is still considered a national model (FISA Foundation, 2015).

Advocacy and activism efforts are still very much alive in Pittsburgh. July 2015 marked the 25th anniversary of the passing of the Americans with Disabilities Act (ADA)
and in tribute of this landmark legislation, the disability community planned events across the county. These celebrations raised awareness about disability and stigma, educated community members on the value of inclusion and access, and provided all members of the community opportunities to connect and learn from one another. The ADA 25 celebration included everything from the Reel Abilities Film Festival, a disability themed film festival; the Carnegie Library Summer Reading Extravaganza, which distributed information on literacy, accessibility, and gave out booklists of disability-themed books; and in June 2015 the Pittsburgh Symphony Orchestra became the first full orchestra to offer a sensory-friendly performance with their performance entitled “Celebrate Pittsburgh.” There were other local events held across the county and the city also partnered with the national disability social justice movement by hosting the National Council on Disability’s annual meeting in May 2015 (FISA Foundation, 2015).

The disability community in Pittsburgh remains invigorated and effective in large part due to their sizeable and visible roster of proud allies, partners, and agencies. Successful collaborative efforts involving shared goals and joint decision-making have allowed a multitude of stakeholders, those conventionally associated with disability and others, to demonstrate agentic leadership. The disability community will continue to gain momentum if the issues they champion are reframed from “disability issues” to “all-community” issues.

**Addressing the Needs of the Disability Community**

Pittsburgh advocates have a respected and well-deserved reputation for being able to energize community partners, inspire action on individual and organizational levels, and effectively lobby for policies and legislation that affirm and support disability rights.
When it comes to securing access, opportunities, and inclusion for the disability community, Pittsburgh is a well-known home of industries and nonprofit organizations that meaningfully engage with, gainfully employ, comprehensively educate, and invest in individuals with disabilities. The Pittsburgh community has a multitude of agencies, organizations, proud self-advocates, and family advocates that have not only responded to the needs of individuals with disabilities but developed innovative services, programs, assistive technologies, and experiences to meet the evolving demands of individuals with disabilities in an ever-changing world.

**Employment.** In the realm of employment, Bender Consulting Services, Inc., a nationally renowned Pittsburgh-based agency, recruits and hires people with disabilities for competitive career opportunities in the public and private sectors (Bender Consulting Services, Inc., 2015). #I Want to Work is a self-advocacy campaign powered by young Pennsylvanians with disabilities who, with support from the United Way, work towards ensuring that other young adults with disabilities get the employment opportunities they deserve (#I Want to Work, 2015). These organizations champion and facilitate competitive employment opportunities for individuals with disabilities and provide space for young adults with disabilities to develop as advocates. They share a mission of empowering individuals with disabilities and improving quality of life for members of the disability community. The staff at Bender Consulting Services, Inc. and the youth advocates at #I Want to Work undeniably believe that disability rights are a matter of social justice.

**Education.** Access to a free and appropriate public education in the least restrictive environment is a right for all children with disabilities, protected under the
Individuals with Disabilities Education Act (IDEA). However, enforcement of disability legislation, including the Americans with Disabilities Act, is predominantly a complaint-driven process. This has placed the responsibility of reporting access issues almost exclusively on parents. Pittsburgh parents are no exception and their energy has generated many impactful and advantageous initiatives that have led to more special-education-related gains. Collaborative efforts on the part of parents, service agencies, county offices, schools, and youth have generated the 21 and Able Initiative and the creation of the Pennsylvania Youth Leadership Network (PYLN).

The 21 and Able Initiative works to support youth with disabilities after they graduate from high school by advocating for programs, expanded services, and increased opportunities that can provide a better quality of life (United Way of Allegheny County, 2015). This initiative, led by the United Way and dedicated families, tackles the continuum of transition issues, including housing and employment barriers, but their attention to education issues has been pivotal. A vital tool developed by the 21 and Able Initiative in partnership with the Pennsylvania Bureau of Special Education and the Pennsylvania Training and Technical Assistance Network (PATTAN) is the “Planning for the Future Checklist.” This checklist guides youth with disabilities and their families through their transition from high school to higher education or the world of work. The checklist suggests the types of conversations, actions, connections, and skills youth should practice from 14-21. These prompts encourage youth to speak up at IEP meetings, participate in extracurricular activities, apply for services at the Office of Vocational Rehabilitation, take the necessary steps to manage their health, and other tasks that will support them as they navigate life’s transitions.
Another Pittsburgh initiative that was born from the struggles young advocates experienced and their commitment to make change is the Pennsylvania Youth Leadership Network (PYLN). PYLN is a disability advocacy group that is designed and directed by young adults with disabilities with the primary objective of helping other youth develop advocacy skills. The members of PYLN have created educational toolkits for youth and their parents, provided resources and opportunities for youth to learn more about disability and advocacy, and led webinars, workshops, and hosted conferences to build a well-knit community (Pennsylvania Training and Technical Assistance Network, 2015). PYLN’s partnership with PATTAN affords them the opportunity to connect with educators across Pennsylvania to address barriers to inclusion in classrooms, schools, and districts. The parents supporting the 21 and Able Initiative and the youth advocates in PYLN undeniably believe that disability rights are a matter of social justice.

**Healthcare.** The Children’s Hospital Advisory Network for Guidance and Empowerment (CHANGE) is a youth led, youth driven program that works to ensure successful transition to adult lives for individuals who will face, face, and have faced transitional barriers in healthcare (University of Pittsburgh Leadership Education in Neurodevelopmental Disabilities and Related Disorders (LEND), 2015). CHANGE board members, who all have disabilities or live with chronic medical conditions, believe that being able to safely and effectively manage your own health leads to a more independent, better quality of life. The CHANGE board, in conjunction with Children’s Hospital and other community partners, has developed videos demonstrating the value of a youth-centered approach to healthcare transition, organized a conference for youth transitioning from adolescent to adult medicine, and shaped policies and procedures at Children’s
Hospital to better reflect the needs of patients between the ages of 16-26. CHANGE board members work diligently to support their peers and educate clinicians on how to best approach, address, and accomplish healthcare goals. Empowering other young people to advocate for their needs and illustrating to clinicians and practitioners the value of youth voices in managing healthcare is beginning to shift the responsibility of managing health needs, and thus the ability to lead an independent life, to a much more capable and confident patient cohort (LEND, 2015).

Similarly the Epilepsy Foundation of Western/Central PA seeks to empower individuals living with seizure disorders to overcome challenges, build leadership skills, and shape policy. A key component of their work is educating the community about epilepsy, advocating for equity and inclusion in all domains of life, and connecting with others who have epilepsy locally, nationally, and internationally to inform the type of action being taken at their respective homes. The Epilepsy Foundation’s blossoming young adult leadership program, the Youth Council, promises to recruit, train, and support young people living with epilepsy to develop their own awareness initiatives, work on the policy level, and accomplish personal goals (Epilepsy Foundation, 2015).

Epilepsy is a neurological disorder that affects more than 2.5 million Americans and often times it can be treated effectively through medication, special diets, or surgery. With more education, outreach, and proactive approaches to empower individuals with epilepsy, youth can establish and accomplish health care, education, and other meaningful goals (Epilepsy Foundation, 2015). The CHANGE program and the Epilepsy Foundation of Western/Central PA are two more groups who also undeniably believe that disability rights are a matter of social justice.
Independent living and quality of life. Recreational and competitive sports provide individuals the opportunity to practice teamwork, exercise discipline, achieve health goals, and boost self-confidence. Providing individuals with disabilities the same opportunities is integral to maintaining an inclusive culture. Adaptive sports engage individuals with different athletic abilities in a meaningful way. Pittsburgh has a variety of agencies and teams that specialize in adaptive sports. While some adaptive sports programs lead with the therapeutic benefits of athletic involvement, others promote the social development gains that one can acquire from playing sports.

Three Rivers Adaptive Sports offers year round sports and recreation opportunities for individuals with disabilities and their families to promote quality of life (Three Rivers Adaptive Sports (TRAS), 2015). Mighty Penguins Sled Hockey operates therapeutic and competitive ice hockey programs for individuals with disabilities to develop character, sportsmanship, and physical fitness while promoting and encouraging both educational and cultural experiences (Mighty Penguins, 2015). Dan McCoy is a Paralympic gold medalist from Pittsburgh who started playing hockey in 2003. McCoy’s commitment to his team, hockey, and advocacy efforts are quite apparent, as he has spoken to diverse audiences about sportsmanship, persistence, and the merits of athletics that are accessible to all people (USA Hockey, 2015). McCoy spoke at the Reel Abilities Film Festival in October 2015 about the advantages of playing sports and the ultimate outcome of developing skills and competencies that can be translated to other pursuits (FISA Foundation, 2015). McCoy is currently attending the University of Pittsburgh, where he is pursuing a degree in rehabilitation science and sports medicine (USA Hockey, 2015).
The Three Rivers Center for Independent Living (TRCIL) strives to empower people with disabilities to enjoy self-directed, personally meaningful lives by providing outstanding consumer-controlled services and by advocating for effective community change. TRCIL not only works on the individual level to equip individuals with self-advocacy skills but also challenges physical, attitudinal, communication, and systems barriers. TRCIL’s staff members offer trainings addressing a multitude of life skills, such as household budgeting and financial management, utilizing public transportation or local Para transit services, support navigating the social services system, problem-solving techniques, and personal safety.

While TRCIL works with the entire disability community, their Youth Empowerment for Success (YES!) program specifically engages young people with disabilities to provide skill training and opportunities to practice becoming competent advocates who can confidently live independently. YES! provides youth with disabilities one-on-one and group training to address skills needed to transition from high school to higher education, employment, and independent living (TRCIL, 2015). On a platform of comprehensive inclusion, equitable opportunities, and guaranteed access, TRCIL ultimately pursues a world in which people with disabilities can fully participate in all aspects of society. The adaptive sports programs in Pittsburgh and TRCIL undeniably believe that disability rights are a matter of social justice.

For all of these agencies and the many other service providers in Pittsburgh the central purpose of their work is maximizing opportunities for individuals with disabilities to have a better quality of life, live independently, and be empowered to make autonomous decisions, navigate systems as competent advocates, and champion disability
rights as a matter of social justice. While these agencies instrumentally help the disability community it is important to temper the power of these service providers with empowering youth with disabilities to make their own decisions, accomplish their own goals, and lead their own lives. It is imperative that we continue to create productive partnerships between individuals with disabilities and other members of our community so that our cultural narrative of disability truly reflects the experiences of those living with disabilities. Without fostering a capacity for agency in youth with disabilities our cultural understanding of disability and our ability to authentically practice inclusion will continue to be saturated either by accidental manifestations or deliberate perpetuations of ableist constructs, themes of inspiration porn, and utilization of the medical model and charity model of disability.

**Disability-Positive Environments in Pittsburgh, PA**

The current disability advocacy infrastructure in Pittsburgh supports and serves a wide spectrum of youth with disabilities but some of these programs, recreational opportunities, and skill-building groups are lacking in regard to how they intentionally and effectively empower youth as competent and capable agents. My work in Pittsburgh has contributed to my belief that creating disability-positive environments will target and improve the efforts of an already promising advocacy network. The central focus of my research is working with young professionals with disabilities to gain a better understanding of what it is like living with a disability, developing an identity, and maturing as an agent in the context of past participation in a disability advocacy program in Pittsburgh, PA. Thus, this research aims to learn from young professionals with disabilities how disability-based programs influence their relationship with expectations,
goals, success, and their overall practice of agency. Investing in the personal narratives of the adults participating in these groups, programs, and opportunities is clearly vital. Without the wealth of information provided by their phenomenological experiences and genuine stakeholder engagement, I myself perpetuate ableism by speaking for a token group instead of partnering with youth who have valuable insight.

As discussed in the previous section, in order to support youth with disabilities in their transition journey, a multitude of youth-targeted programs have been developed to engage, empower, support, and sustain agency. The Bender Lead on Team, PYLN, CHANGE, and the Mighty Penguins are just a few youth-centric groups that pledge not only to assist young advocates as they navigate life but also incorporate their perspectives, ideas, and goals into their missions and vision statements. Stakeholder investment is paramount in order to maintain relevance, substantiate program initiatives, and continuously shape a safe environment for intended consumers. Challenging our cultural narrative of disability means providing more opportunities for youth to develop their capacity for agency. Shifting the ableist paradigm of disability towards embracing disability-positivity requires programs that both honor the experiences of youth with disabilities and acknowledge their learning needs. I propose that disability-positive environments provide opportunities for skill building, practicing advocacy, and supporting youth with disabilities as they explore their self-efficacy and establish goals within a safe, culturally competent, and inclusive framework. This system maintains high expectations and promotes authentic learning for youth with disabilities who are framed as autonomous, agentic leaders.
Ultimately the main objective of disability-positive environments is to empower youth with disabilities to author their own disability narratives. Through guided opportunities for conscientious reflection, youth with disabilities can process their perceptions of identity, disability, and agency. In addition, as youth with disabilities develop mutually beneficial partnerships with peers and adults based on shared goals and joint decision-making, they acquire the ability to form productive relationships, utilize local resources, and understand the merits of social networks. Another key goal of a disability-positive environment is instilling youth with the capacity and competency to transfer skills from the context of a disability-positive environment to every day life, demands, experiences, and opportunities.
Disability-positive environments provide an optimal space for youth with disabilities to grow as advocates, agents, and leaders who can exact ownership of their goals, decision-making, learning trajectories, and accomplishments. However successfully exemplifying and applying disability-positive principles while treating youth with disabilities as agentic leaders is a notable challenge. Similar to youth-adult partnerships, operating a disability-positive environment comes with its share of pitfalls and barriers that take creativity, collaboration, and commitment to repair. The overall culture of a group, the methods through which youth are engaged and supported, and the ability of young people to accomplish personal goals as well as contribute to larger programmatic goals, plays a pivotal role in the healthy functioning of a disability-positive environment. Many disability-centric youth groups aspire to respectfully, meaningfully, and holistically bring youth voice and youth vision to the forefront of their work but the lack of replicable models, financial resources, and social capital can impede the formulation of potential disability-positive environments.

Throughout my career I have had the pleasure to work with many adolescents and young adults with disabilities who are eager and earnest leaders but struggle with actual agency and introspective self-awareness. These youth are often quick to identify as self-advocates but struggle to apply this construct in their everyday life. Many can define the term in a generic way but cannot incorporate it into their own identity or actually apply it in reaching personal goals. For many individuals with disabilities in Pittsburgh, identifying as a “self-advocate” is more about the title than exercising actual agency. Our young people with disabilities have the potential but not necessarily the confidence to be
effective agents in different arenas of their life (healthcare, education, and employment systems).

Ultimately, saying you are a “self-advocate” using recycled language and a definition that is not personally relevant is very different from defining your own identity, understanding your disability, establishing goals, and using your own voice to articulate how you can be successful. A better understanding of how to structure and operate disability-positive environments with fidelity and validity, data on how youth perceive these environments in regard to impacting their every day life, and insight into how self-perception in relation to identity and disability influence the effectiveness of disability positive-environments is sorely needed to shape our disability narrative and positively impact outcomes for youth with disabilities.

In conclusion, authentic disability-positive environments serve as valuable learning opportunities in which youth with disabilities can cultivate a perception of the self as a capable actor who can positively impact the community as an advocate, leader, citizen, activist, and dedicated learner. This has the potential to contribute to a new ideological approach for understanding disability, defining disability, talking about disability, and setting expectations for youth with disabilities. Youth with disabilities must challenge their understanding of disability as being “exceptional,” “inferior,” or just a normal part of the human condition. We all need to remember that the person comes first. A diagnosis does not tell you anything about an individual’s passions, ambitions, or motivations. The diagnosis does not define them but their actions and accomplishments do. It is important to remember the words of renowned advocate Stella Young (2014): “disability isn't exceptional.” We need to hold high expectations for youth with
disabilities because just having a diagnosis isn't enough; they have to decide who they are, act like the person they want to be, and be proud of who they become. They need to make those decisions in order to live their own life.

Justification for Study

My professional experiences in the disability field, the research from the literature, and my own personal relationship with disability have shaped my belief that the phenomenon of living with a disability, particularly as a young adult, and the concept of disability-positive environments demand further research (Braun and Clarke, 2006; Ritchie and Spencer, 1994 as cited in Brooks, et al., 2015). The research and information compiled in the literature review situates this work using a phenomenological framework that examines how disability is experienced and perceived by individuals labeled as “disabled.” This work is also significantly influenced by the field of disability studies, which contends that exploring different cultural models of disability, like the medical model of disability and the social model of disability, provides valuable insight as to how a personal “disability narrative” is authored (Adams et al., 2015). The literature also suggests that the fusion of social cognitive theory and the youth-adult partnership model can positively influence how youth with disabilities mature as causal agents. I developed the operational definition for disability-positive environments by combining these two frameworks—integrating the development and application of self-efficacy, agency, goal attainment, and reflection with the interplay between leadership development, shared vision, and joint-decision making (Bandura 1989, 2001; Camino, 2005; Zeldin, 2014). Disability-positive environments, a well-scaffolded comprehensive schematic framework designed to improve agency, can be customized in order to meet the needs of individuals.
who are at different places in regard to their personal development, skill-level, and goal development, thus embracing phenomenology’s emphasis on the person and their unique experience.

The mission of my research is to learn from young professionals with disabilities, through personal narratives and conscientious reflection, what it is like living with a disability, developing an identity, and maturing as an agent in the context of past participation in a disability advocacy program in Pittsburgh, PA. I seek to better understand how young professionals with disabilities acknowledge, appreciate, and articulate their disability, their identity, and capacity for agency both reflecting retroactively as youth enrolled in disability advocacy programs and as current professionals. The methods used for this study aimed to answer the following primary research question: How and to what extent do youth with disabilities perceive disability advocacy programs in Pittsburgh as disability-positive environments? The study also explores the following supplemental research question: How do young professionals with disabilities perceive and describe living with a disability, developing an identity, and maturing as an agent in the context of past participation in a disability advocacy program?

My research questions are driven by principles of phenomenological epistemology, as I have been intimately involved with the study and experience of disability my whole life. The decision to employ an epistemological approach was based on its call for transparency—being explicit about one’s own epistemological assumptions (Braun and Clarke, 2006 as cited in Brooks, McCluskey, Turley, and King, 2015). As I am clearly not an objective observer, reporting on my own assumptions, reflecting on my
bias, and challenging preconceived ideas was an important aspect of my study. I used Template Analysis to analyze my data as it allows researchers to begin data collection with a priori themes—themes identified in advance based on personal and professional experiences as well as a review of the literature that serve as a springboard.

In closing, as my literature review emphasizes, adopting a disability-positive narrative is a matter of social justice. This counter-ableist narrative must frame disability simply as a part of our every day world and not a deciding factor in employment, education, healthcare, or quality of life outcomes. Our young adults with disabilities need to discover their purpose and establish goals that are personally significant. These accomplishments should reflect their authentic ambitions and facilitate honing critical problem solving and learning skills. Individuals with disabilities must be held accountable for their accomplishments as well as have the advocacy, activist, and agentic leadership skills necessary to embrace and build off their own achievements. When youth with disabilities have a higher capacity for agency they are increasingly likely to navigate life’s many transitions successfully. When youth with disabilities have positive disability identities, increased literacy when it comes to disability awareness, and they operate as effective agents, they are more likely to transition into adults who are more fulfilled, experience positive outcomes, and have a fully actualized perception of disability’s role in society.
Chapter 3

Methods

The methods used for this study aimed to answer the following primary research question: How and to what extent do youth with disabilities perceive disability advocacy programs in Pittsburgh as disability-positive environments? The methods also examine the following supplemental research question: How do young professionals with disabilities perceive and describe living with a disability, developing an identity, and maturing as an agent in the context of past participation in a disability advocacy program?

This study was designed to learn how alumni of various disability programs perceived their disability and identity during their youth and how that may have influenced current self perceptions, their assessment of disability advocacy groups, and how their relationship with expectations, goal setting, and goal attainment has or has not changed as they’ve transitioned into adulthood. Non-probability sampling methods were employed in order to recruit participants. I used a voluntary sample as well as a convenience sample to recruit study participants. The recruitment process consisted of contacting eligible individuals via email and requesting their participation in the study. Ten participants were included in the study.

This study collected qualitative perceptual data. Template Analysis was utilized as a methodological and analytical approach as it allows the researcher to utilize a priori themes derived from past research, literature, and professional experiences. These themes served as a springboard to shape the development of the study’s instrument as well as enable the exploration of rich narrative data in significant detail. Participants were
interviewed in person, one-on-one, and a semi-structured instrument—the Perceptions of Disability Instrument—guided the interview. The Perceptions of Disability Instrument consists of six sections, or a priori themes, that were shaped by the literature. The questions asked the participants to discuss disability, identity, agency, goal setting, disability advocacy programs, and their current relationship with the disability community. After preliminarily, initial, and finalized coding I was able to create a coding template that I could apply to the entire data set in order to elucidate any permeated themes. Four integrative themes were found that yielded the creation of the conceptual framework, the Path of Advancement for Development of Positive Disability-Identities, which is discussed in considerable detail in Chapter 4: Findings and Discussion.

Research Design

Utilizing my professional network of self-advocates, I recruited ten young professionals with disabilities and interviewed each of them individually to answer my research questions. This study was designed to provide a more detailed look into how these adults perceive their past involvement with disability advocacy programs in relation to defining their disability, identity, and capacity for agency; capture their personal narratives and reflective assessments regarding the effectiveness and satisfaction level of the program; explore how their relationship with expectations, goal setting, and goal attainment influenced their life; and overall this study delved into how the participants’ definitions of disability, identity, and agency have changed over time. The qualitative interview data was analyzed via Template Analysis. The a priori themes used in data collection and data analysis were informed by the literature, the context review, and my experience with disability as a practitioner and self-advocate. These experiences directly
shaped my epistemological assumptions and the literature emphasized the importance of studying the relationship between agency and the healthy development of youth with disabilities. The use of Template Analysis allowed me to examine my data and elucidate key findings that addressed disability, identity, capacity for agency, and the power of narrative.

Sample Selection and Recruitment of Participants

Non-probability sampling methods were employed in order to recruit participants. I used a voluntary sample as well as a convenience sample to recruit study participants. These sampling methods were utilized because the study called for successful, young professionals with disabilities. The criteria I developed to define a “successful, young professional with a disability” was informed by the literature and actual advocates in my advocacy network. I defined “success” as being reflective of past accomplishments, employment history, presence in the disability community, and higher education degrees. I had existing relationships with all of the participants due to our overlapping professional interests, shared success level, and advocacy reputations. The details of the participants’ achievements are explored in depth in Chapters 4 and 5. In addition to being successful, eligible participants were also young professionals with disabilities who participated in a disability advocacy program as a youth or young adult.

The recruitment process consisted of contacting eligible individuals via email and requesting their participation in the study. I contacted fifteen young professionals with disabilities whom I knew from the disability community whose experiences would inform my work. Nine participants emailed agreeing to participate. The tenth participant had been forwarded my email by one of the individuals I had directly contacted; the
individual I contacted directly did not participate. While I had not initially emailed the tenth participant, when she received the forwarded email she was very interested in participating and contacted me via email. Ten participants were included in the study.

In sum, all of the participants were self-selected successful young professionals with disabilities who participated in a disability advocacy program as a youth or young adult. The participant pool was cross-disability and it did not include members of protected groups. The justification of my sample is that in order to answer my research questions I needed to interview individuals who by all accounts thrive in the community as indicated by their careers, degrees, and reputations as advocates. Through my preexisting relationships with these advocates, I knew they were all successful and they all had defined their relationship with disability and identity in a manner that enabled them to achieve their goals. As these individuals were all self-described advocates, they were used to sharing their disability histories and explaining their identities as agents. By recruiting individuals who had well-rehearsed narratives, established disability-identities, and already perceived themselves as agents, I was able to use perceptual data to answer my research questions in an efficient and cost effective way.

Data Collection

Template Analysis, a style of thematic analysis, is an appropriate methodological approach to utilize in order to answer research questions that aim to identify patterns of meaning across a qualitative dataset. Data that is collected via interview transcripts and open-ended questions and responses on written questionnaires are the types of data that are best evaluated with Template Analysis in order to discern more detailed findings (Brooks et al., 2015, p. 203). This study collected perceptual data in order to answer the
research questions. Utilizing Template Analysis I was able to explore the richest aspects of my data with the most flexibility and with the most depth (Brooks, et al., 2015). I used Template Analysis to analyze my data as it allows researchers to begin data collection with a priori themes. My study’s a priori themes were identified in advance based on my aforementioned personal and professional experiences as well as a review of the literature. For my study, Template Analysis was approached in a deductive, latent, and constructionist way (The University of Auckland New Zealand, 2016). My a priori themes were derived from the fundamental components of disability-positive environments, which likewise informed the development of the study’s semi-structured questionnaire, the Perceptions of Disability Instrument.

**Procedures.** This study collected qualitative, perceptual data through in-person interviews guided by a semi-structured instrument, the Perceptions of Disability Instrument, which was referred to as a questionnaire. The questionnaire was designed to give the participants the opportunity to share their narratives with a suggested structure that helped keep the interview on track. Participants were interviewed in person, one-on-one. Participants had as much time as they needed to complete the interview. In respect of the participants’ busy schedules, they were asked to select the date, time, and interview location. They were notified that the interview questions might elicit the sharing of sensitive personal experiences so they should choose an interview location where they feel comfortable talking about potentially sensitive issues, like experiences with discrimination and childhood memories.

The participants chose a variety of locations to conduct their interviews. One female participant and a gender fluid participant were interviewed at coffee shops that
were near their homes and places of employment. The three male participants were interviewed at their place of employment during the workday. Three female participants were interviewed at restaurants, one during lunchtime and the other two during dinnertime. One female participant asked to be interviewed at her home and the remaining female participant was interviewed at the student center on her university’s campus. The participants spoke candidly about their experiences in environments where they were likely to be overhead, indicating a level of comfort and a strong sense of openness with their personal stories. The four participants who had their interviews in private spaces, at their place of employment and at their home, did share that they chose those venues out of convenience due to being busy with school and work responsibilities. During the scheduling process, Interviewee 5, who was interviewed at her home office, stated that she wished we could meet at her local coffee shop but she had to concentrate on getting school work done, which was best accomplished at her home.

The consent form was provided to participants prior to the study via email. The consent form included instructions on how to request accommodations for the interview but none of the participants required supports. All of the participants were familiar with study protocol due to past participation in research studies, past experience conducting studies for their own research and employment ends, or both. It can be suggested that this familiarity contributed to the fact that none of the participants asked for clarification about the consent form or the study overall. It is also important to note that I knew all of the participants from joint advocacy efforts, shared experiences on work and school projects, and volunteer opportunities. All of the participants were colleagues whom I had met through initiatives that addressed disability in some way. For the participants and
myself, disability was a comfortable topic in both personal and professional settings; each participant and I had had conversations about disability in the past.

Participants were provided a copy of the Perceptions of Disability Instrument at the start of the interview. This questionnaire was designed to capture data that: addresses how adults with disabilities articulate their personal experience with disability, reflects how adults with disabilities perceive their past experiences with disability advocacy programs, outlines the participant’s relationship with setting and achieving goals and discerning expectations, examines how participants assess their respective youth programs, and finally captures data detailing each participant’s involvement with the disability community. These in-person interviews were transcribed on a laptop. The participants were told during the interview and in the consent form that only the researcher had access to the completed questionnaires for coding purposes. All materials were protected. No sensitive information was requested of the participants. Participants were told that upon completion of the interview there were no additional study requirements.

**Instruments.** Participants were provided a copy of the Perceptions of Disability Instrument at the start of their interview. This instrument, which was referred to as a questionnaire for the participants, was designed to capture data that: addresses how adults with disabilities articulate their personal experience with disability, reflects how adults with disabilities perceive their past experiences with disability advocacy programs, outlines the participant’s relationship with setting and achieving goals and discerning expectations, examines how participants assess their respective youth programs, and finally captures data detailing each participant’s involvement with the disability
community. The Perceptions of Disability Instrument consists of six sections. The Study Background section provides the research questions and operational definition for disability positive-environments. The Disability, Identity, and Agency section collects information on perceptions of disability, identity, and agency as a youth and as an adult. The Experience With Disability Advocacy Programs section asks the participant their feelings regarding joining and belonging to a program as a youth and as an adult. The Exploring Goals section seeks to discern the participant’s level of prioritization and interpretation of goal setting both retroactively and currently. The Program Assessment section is designed to collect information on participant’s assessments of their respective program. Finally, the Present Relationship with the Disability Community section establishes the participant’s current type of involvement with the disability community.

The a priori themes in this questionnaire were identified in advance based on their helpfulness and relevance in regard to answering my research questions. However, in accordance with Template Analysis methodology, these themes were tentative and subject to be redefined as the data underwent the six steps of Template Analysis (King, 2012 as cited in Brooks et al., 2015).

The data was collected using a semi-structured interview that was guided by the Perceptions of Disability Instrument that was developed for this study. The instrument listed specific questions but also provided participants the opportunity to share their narratives. I initially intended to conduct the interviews by asking every question from the questionnaire and then providing time for the participant to elaborate on any themes, add additional ideas, and contribute recollected experiences.
An unexpected and salient finding was that the participants did not talk about their past experiences with advocacy groups in relation to the formation of their current identities, nor did they answer questions about disability-positive environments. Every participant’s narrative shifted focus when I came to the *Experience with Disability Advocacy Programs* section of the questionnaire. Instead of answering the questions in this section, each participant dedicated the majority of their interview towards sharing their unique narrative that: explored pivotal experiences that occurred during their childhood, adolescence, and young adulthood as individuals with disabilities; delved into how they cultivated, defined, and internalized their disability-identity; and examined how their achievements and broad sense of purpose provide context for future plans. Their narratives were not shared through the lens of being a member of a disability advocacy program, but as individual advocates. These findings are discussed in considerably more detail in Chapters 4 and 5.

Ultimately I did not ask many of the questions on the questionnaire because I did not want to interrupt the participants’ storytelling. Instead I asked follow-up and clarification questions as new information organically surfaced. I was able to probe deeper into new topics and insights using follow-up questions that consisted of elements of social cognitive theory, the youth-adult partnership model, and principles of disability-positivity. In closing, using Template Analysis and a semi-structured interview was pivotal in that it provided the flexibility for me to dig deeper and learn more from my participants about their experiences and perceptions, and benefit from their expertise.
Data Analysis Methods

I used Template Analysis to analyze my data as it allows researchers to begin data collection with a priori themes. My study’s a priori themes were identified in advance based on my aforementioned personal and professional experiences as well as a review of the literature. For my study, Template Analysis was approached in a deductive, latent, and constructionist way (The University of Auckland New Zealand, 2016). My a priori themes were derived from the fundamental components of disability-positive environments, which likewise informed the development of the study’s semi-structured questionnaire, the Perceptions of Disability Instrument.

At the start of the interview the participants answered questions from the Perceptions of Disability Instrument but the focus of their narratives shifted when I began asking questions from the Experience with Disability Advocacy Programs section. Instead of answering these questions, the participants began discussing pivotal experiences that occurred during their childhood, adolescence, and young adulthood as individuals with disabilities; their stories were not shared through the lens of being a member of a disability advocacy program. Data collection thus shifted from transcribing answers to pre-written questions to transcribing the entire interview at length. The six steps of Template Analysis were used in order to identify patterned meaning across interviews (King, 2012 as cited in Brooks et al., 2015). Template Analysis requires familiarizing yourself with the data, which entails many re-reads, revisits, and recoding of your dataset. Preliminary coding is conducted in order to highlight anything in the data that might contribute to answering your research questions. Template Analysis was selected as my methodological approach due to its utilization of a priori themes, which
allow the researcher to create a flexible, tentative template based off of personal experiences, work experiences, and the literature. In sum, a priori themes provide a springboard to begin the data collection process.

After reviewing the individual interview data numerous times, I created a preliminary Google Spreadsheet coding template consisting of a priori themes. Data was organized by the following a priori themes pulled directly from my operational definition of disability-positive environments: skill building, advocacy opportunities, goal setting, assessments of societal expectations, authentic learning experiences, and perceptions of the self as autonomous agentic leaders. However this initial organization of the data in the preliminary coding template failed to capture the richness and breadth of the participants’ narratives. The scope was much too narrow to accurately reflect the participants’ experiences and perceptions and this constricted lens did not allow the participants’ own words to emerge from the data. In response I restructured the template to better fit the data and reorganized emerging themes into more meaningful clusters to start defining relationships within the data.

The second Google Spreadsheet I drafted, which will be referred to as the initial Google Spreadsheet coding template, in alignment with the terminology used in Template Analysis, organized the data first by the participants’ experiences as youth and second by their experiences as young adults. The proposed themes consisted of: define disability; list opportunities for advocacy; awareness of disability or difference (later referred to as “disabling difference”); the role of family; the role of friends and romantic partners; disability and authority figures, service systems, and society; define identity; define agency; disability programs and experiences; and define goals. In addition to these
proposed themes, the following additional themes were later added based on patterned meaning drawn from the participant data: “practicing self-care” and “what I would do differently as a youth.” These themes permeated almost every participant’s interview data and the synthesis of these themes lent to the creation of a more structured, finalized Google Spreadsheet coding template. I was then able to apply this finalized Google Spreadsheet coding template to the entire dataset. In order to organize the data further I pasted direct quotes from the interviews into the finalized Google Spreadsheet coding template and this ultimately shaped the overall interpretation and articulation of the data.

After applying the finalized Google Spreadsheet coding template I was able to draw emerging latent and constructionist themes from the data that served to develop a discernible thesis that captured the participants’ narratives. A significant part of this process was elucidating integrative themes that permeated the entire dataset. Four integrative themes were deduced from the data, which served as the bedrock of my conceptual framework entitled, the Path of Advancement for Development of Positive Disability-Identities. This conceptual framework is examined in considerably more detail in Chapter 4: Findings and Discussion.

In closing, this study was designed to generate narratives that detailed the phenomenological experience of living with a disability as a youth and as a successful young professional. Guided by interview questions that spanned adolescent through present day experiences, the participants discussed their disability-identities, their exposure to principles of disability-positivity, their evolving perceptions of individualized values, purpose, capabilities, and accomplishments, as well as insight into how they articulate and value the concepts of identity, disability, and agency. I focused on the
participants’ perceptions, assessments of personal experiences, and their individually constructed theories of knowledge. Altering our ableist disability narrative is a matter of social justice because without serious attitudinal shifts our youth with disabilities will continue to be confined in a culture of low expectations that promotes underdeveloped agency. The outcomes of this study have provided unique insight into the subject matter and have helped build a foundation for the development of generative next steps. My findings, framework, next steps, and related implications are discussed at length in Chapters 4 and 5.
Chapter 4

Findings and Discussion

This study sought to answer two research questions. The primary research question was: How and to what extent do youth with disabilities perceive disability advocacy programs in Pittsburgh as disability-positive environments? And the supplemental research question was: How do young professionals with disabilities perceive and describe living with a disability, developing an identity, and maturing as an agent in the context of past participation in a disability advocacy program? The objective of this study was to provide a more detailed look into how young professionals with disabilities described these youth programs and if they drew comparisons with disability-positive environments. One-on-one interviews were conducted with each participant and the interview was guided by a semi-structured questionnaire that was comprised of questions focused on the disability experience spanning from adolescent years through present day experiences. I had hoped to learn more about how participants’ disability-identities matured in relation to participation in youth advocacy programs, delve into their exposure to principles of disability-positivity, and explore their perception of their youth program in relation to my definition of a disability-positive environment.

There was no minimum or maximum time requirement for the interviews and I told the participants, who from here on out will be referred to as interviewees, that they determined the length of the interview. While I had assumed interviews would take anywhere between an hour and ninety minutes, I found that the shortest interview was ninety minutes long and most lasted about two hours, the longest of which lasted four hours. In fact one interviewee emailed me the day following her interview to share more
thoughts and elaborate on some questions. The interviewees were unanimously eager to participate and their answers were honest and transparent. They shared memories, experiences, ambitions, as well as a multitude of introspective realizations concerning living with a disability through coherent and well-structured personal narratives. It was quite apparent that this was not the first time the interviewees had shared their stories; they were seasoned narratives. In a community that values rich narratives regarding disability, ability, and success, these interviewees, who are top-performing young professionals with disabilities, were open about their involvement with the disability community as advocates, leaders, and role models. In other words, they are experienced storytellers.

**Profile of Each Interviewee**

All of the interviewees are young professionals with disabilities who: work directly with disability (youth development, college support services, etc.), work in the human services field (social work, education, community organizing, etc.), or work at a non-profit that has a strong advocacy and social justice focus. All of the interviewees have publically self-disclosed their disability and identify as a disability advocate. Each interviewee brings their personal experience living in an ableist system to their place of employment, to their educational experiences, when accessing both public and private resources (transportation, recreation and leisure opportunities, etc.), and navigating relationships. All of the interviewees were vocal about exercising their capacity for advocacy during interactions with a wide spectrum of individuals, institutions, and systems. However, please note that the interviewees had varying disabilities, races, genders, backgrounds, and experiences both as youth and currently as young
professionals. The interviewee profiles below provide a snap shot of each interviewee’s basic demographic data, disability, background, any pertinent information, and how they answered the first question on the Perceptions of Disability Instrument, defining their disability, identity, and agency.

Interviewee 1 is a Caucasian woman who uses a wheelchair and is currently working on her Master’s degree. Interviewee 1 was the only interviewee to talk about the role religion plays in her life. Interviewee 1 explained that being independent is incredibly important to her and her ability to advocate and secure access to concert venues, amusement parks, plays and musicals, and sporting arenas is paramount in the definition of her identity. Interviewee 1 articulated that her decision to plan, pay for, and attend cultural events is reflective of who she is, someone who won’t be limited by stereotypes regarding what she is supposedly capable of. Interviewee 1 also shared that she has been planning to build an accessible waterpark for fifteen years. She perceives this long-term plan as feasible in part due to her belief in God’s providence as well as her independence and adaptability. In regard to her disability, identity, and agency she stated that, “my disability is a part of who I am. I adapt and I have been adapting all my life. I don’t necessarily think of XYZ anymore to make things happen, I just do it – I’m on autopilot. Disability is always there, around me, but I don’t think about it that much – I just navigate my life.”

Interviewee 2 is an African-American man with a mental illness who is an active intersectional advocate and community organizer. During his interview, Interviewee 2 stated that his purpose is to mobilize Pittsburgh’s diverse communities and connect them with national groups in order to dismantle systems of oppression and fight for social
justice with authenticity and integrity. Interviewee 2 spoke of both the external and internal stigma that initially hindered the development of his self-efficacy, self-advocacy, and self-image. Interviewee 2 discussed his liminal position in relation to his work and his identity as he straddles both the African-American and disability community. He explained, “I battle primarily with the intersection of race and disability. The disability community is overwhelmingly white – so I battle racism. Disability is erased and it is more about my race. When I go to communities of color there is rampant ableism so there I am the mouthpiece for disability. Not too many spaces where I can be all of myself – not in the disability or the black community.”

Interviewee 3 is a Caucasian, non-binary individual who is a proud, identity-first autistic advocate. Interviewee 3 was not diagnosed with autism until later in life due to stigma. Interviewee 3 detailed how up until their diagnosis, they struggled significantly attempting to navigate a neurotypical world and identifying as a social being. During their interview, Interviewee 3 discussed how they co-founded an autistic advocacy non-profit that has been built with the scaffolding of intersectional feminist theory, queer theory, and principles of neurodiversity. As an autistic non-binary individual, Interviewee 3’s initial experiences in Pittsburgh’s disability community were limiting; “I’ve been making my own space in the disability community. The autistic community was previously really cis-guy, Aspie culture focused – misogynistic and not LGBT friendly. The disability community in Pittsburgh has been centered on mobility needs and even the rhetoric around it is different than other disability conversations.” Interviewee 3 speaks of their autism, sexual orientation, and gender identity with pride and works to transform Pittsburgh into a more inclusive, integrated, accepting, and stigma-free community.
Interviewee 4 is a Caucasian woman who uses a motorized scooter and assistive medical equipment. Of all the interviewees she has the most extensive history of legislative advocacy, youth development, motivational speaking, and appointments on boards, committees, and workgroups regarding disability issues. Interviewee 4 shared that her formative experiences as a child, being the only student with a significant disability in her school and spending periods of time isolated in the hospital, left her feeling excluded and unwanted. Growing up, Interviewee 4 struggled to find her true self, a sense of purpose, and belonging. In high school Interviewee 4 attended national conferences with other youth with disabilities, which instilled in her a more positive self-image, disability pride, and finally gave her a safe space to reflect on her authentic identity. To quote Interviewee 4 on attending conferences, “for the first time I saw an opportunity where my whole self could serve and be needed. Rather than having to be as nondisabled as possible and only use that nondisabled part of myself to serve, I was able to use my entire self and I would belong and make a difference.”

Interviewee 5 is a Caucasian autistic woman who has an established reputation as an autistic advocate and is currently a doctoral student studying disability and access. Interviewee 5 was not diagnosed as autistic until college due to stigma. After she experienced pronounced issues interpreting social cues and difficulty understanding interpersonal communication and nuance, Interviewee 5 sought an assessment for autism. Interviewee 5 helped co-found an autistic advocacy non-profit and she ensures that the program champions equity, integrity, and identity pride. Interviewee 5 spoke of her own identity as an autistic individual, stating that her “autistic transformation” was a process of “realizing that being autistic defines my entire experience with the world. The
problems I was experiencing weren’t really my fault but a bunch of social issues, social barriers.” Interviewee 5’s identity and purpose focus on being successful in all she does, which requires her learning and applying social rules in a variety of contexts. To quote Interviewee 5, “when I learn the rules of whatever social context I’m in and I’m better than everyone else, that’s success.”

Interviewee 6 is a Caucasian woman with a history of stuttering and selective mutism. Interviewee 6 felt incredibly isolated growing up and her struggle with her stutter and fitting in with her peers significantly contributed to her serious depression and anxiety. Interviewee 6 explained:

I saw myself as two people – my stutter self and my true self. My true self could say all the things I’d want to say if I didn’t stutter and then my stutter self—well, that was my real self, the me who stuttered every day. There was an ocean between the two – a divide – I couldn’t articulate things! I couldn’t cross the ocean to bring my stutter self to my true self – I couldn’t even get it on the boat. It really felt like two different worlds.

Interviewee 6 explained that she did not have many peers with whom she could talk about disability and there was a severe lack of safe spaces, which limited her ability to better understand her disability, self-image, and mental health needs. As an adult Interviewee 6 shared that her ability to bridge her dual identities was a result of practicing self-care, creating her own safe spaces, and nurturing others in both her friendships and professional relationships.

Interviewee 7 is a Caucasian male with an acquired spinal cord injury. Interviewee 7 was injured at the age of 15 and uses a wheelchair. Interviewee 7’s
introduction to disability was through the lens of the medical model. Interviewee 7 was unaware of the existence of a disability community, disability culture, or disability pride as his exposure to disability was either in medical settings or playing wheelchair rugby with males who had similar disabilities. After attending a national cross-disability conference, he realized that all individuals with disabilities experience similar barriers and thus benefit from belonging to a supportive community. Interviewee 7 reflected:

The medical model groups all disability categories together; we are all grouped as being ‘broken,’ but we should be grouped as a ‘community.’ Not just diagnoses. The medical model also says we all need the same things, the same services, and the same treatments – which is not true. Every individual in any type of a community has different needs – don’t stereotype for convenience sake!

Interviewee 7 believes that individuals with disabilities are responsible for bringing visibility to disability in order to challenge stereotypes and expand opportunities for other people with disabilities.

Interviewee 8 is a Caucasian woman with a mild form of cerebral palsy that impacts her mobility. She currently uses a wheelchair. Interviewee 8 discussed how her definition of disability was incredibly disjointed growing up due to the plethora of contradictory messages and negative experiences she was exposed to in her every day life. Lacking role models and positive disability influences, Interviewee 8 had conflicting feelings about what aspects of her disability she should show the world. During her interview she shared stories of using her crutches, using a motorized wheelchair, using a manual wheelchair, and not using any mobility aids at all to look “less disabled” and fit in with her able-bodied peers. Interviewee 8 reflected that she spent so much time
budgeting her energy in order to appear as mobile as possible, that she was emotionally and physically exhausted. For Interviewee 8, defining her disability and learning to live life authentically has been a primary goal. To quote Interviewee 8, “I can do what I can do, I can’t do what I can’t. I have to decide and make the call – and if someone thinks less of me for not climbing stairs, then that’s on them. When I was younger, at times I did too many things to prove myself to other people. It has taken me a long time to own what disability means to me. And it is still a work in progress.”

Interviewee 9 is an African-American man who uses a wheelchair. Interviewee 9 has been a highly active disability leader, advocate, and motivational speaker for many years and has received recognition and awards from numerous disability non-profit organizations in Pittsburgh. During his interview, Interviewee 9 shared that his identity is not defined by his disability, but his charisma, leadership skills, creativity, work ethic, and his “ability to touch lives”; these characteristics all enabling him to challenge social norms and carve his own path. As a youth Interviewee 9 became popular as a survival tactic, saying, “I knew that if I had so many friends then no one would hate me or bully me.” Interviewee 9 has had professional success in both the disability field and in other industries and he chalks these accomplishments up to his ability to authentically connect with different audiences on relevant issues. Interviewee 9 reflected, “I think this skill comes from ‘Young Me’ who was always networking with all the kids at school, who was in every type of friend clique. I learned how to understand different people, respect everyone, how to move back and forth from white folks to black folks, able-bodied folks to folks with disabilities, etc. I see people and meet them where they are.” Interviewee 9
elaborated, “I did things that disabled kids weren’t supposed to do,” which helped lay the foundation for developing his own identity and unique relationship with disability.

Interviewee 10 is an Asian-American woman with spina bifida, who uses a motorized scooter. Interviewee 10 grew up feeling emotionally isolated and physically segregated from her peers due to her mobility impairment. However, Interviewee 10 said despite these challenging experiences she has always been confident and has always recognized her worth. Interviewee 10 cites her family as the driving force behind her resilience, determination, and independence. During her interview Interviewee 10 explained that her family taught her to never say, “no,” and this “stubbornness” has resulted in achieving goals past the typical expectations set for individuals with spina bifida. In regard to disability, identity, and agency, Interviewee 10 stated:

Being visible and being heard is really important for me. I challenge that barrier, of not being seen or heard by society. We live in an able-bodied society with able-bodied expectations and able-bodied norms, but as an individual with a disability you obviously don’t meet some of those so you have to conquer them one at a time. You have a lot to prove. The more I advocate the more my world opens up. My ability to access opportunities increases; I can live based on my own schedule and my own goals—advocacy makes my world open up. Autonomy is everything.

As discussed in Chapter 3: Methods, the interview data was reviewed, reexamined, and organized by themes and subthemes in a Google Spreadsheet. The data was specifically examined through the parameters of social cognitive theory, the youth-adult partnership model, and principles of disability-positive environments. The preliminary spreadsheet organized the data by notating all mentions of skill building,
advocacy opportunities, goal setting, assessments of societal expectations, authentic learning experiences, and perceptions of the self as autonomous agentic leaders in the participants’ narratives; these themes are all essential components of disability-positive environments. However it was actually found that the interviewees did not address the concept of disability-positive environments at all. Each interviewee dedicated the majority of the session towards sharing their unique narrative that explored their experience with disability as children and as young adults, delved into how they cultivated, defined, and internalized their disability-identity, and how their sense of purpose and achievements provide context for future plans—both advocacy goals and individualized goals.

It was also found that all of the interviewees spoke of reclaiming their disability and forging their own identity through the application of self-reflection, establishing goals, and expanding their capacity for agency. The interviewees cited their personal growth as stemming from authentic and intentional learning opportunities that required problem solving skills, critical thinking, and demanded self-efficacy. These rich narratives and their embedded themes of disability-positivity, social cognitive theory, and the youth-adult partnership model were organized under the following integrative themes: avoiding disability, epiphanic experiences, establishing goals and roles, agentic identity and disability-positive narratives, and positive disability-identities. These five integrative themes provided a road map for each interviewee’s self-story, marking the progression and development of their agentic identities as their relationship with disability, identity, agency, and goal attainment was explored within the context of each theme. While each interviewee’s path consisted of unique experiences, perspectives, and ultimately different
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Trajectories, their narratives consistently followed the formation of the five integrative themes, ending with the interviewee in present day as the sole storyteller and primary planner for future goal attainment. In sum, the interviewees’ narratives followed the configuration of the five integrative themes, driven by conscientious reflection, critical thinking, decision-making, pursuit of values, and agency.

Avoiding Disability

In an ableist society, disability is framed as a negative condition that predicts poor outcomes often based on diagnosis alone regardless of the actual individual. This depiction and interpretation of disability as being synonymous with “less-than” is pervasive across institutions and systems and is particularly salient in the media (Love, 2015 as cited in Adams et al., 2015, p. 173; Peters, 1999 as cited in Haller et al., 2006; Haller et al., 2006; Young, 2014). For many young people with disabilities the overly saccharine tropes of inspiration porn as well as negative, highly stereotyped media portrayals of disability can result in internalized ableism (Haller et al., 2006; Young, 2014). In addition, experiences in education settings (Price, 2015 as cited in Adams et al., 2015 p. 64) and medical systems (Davis, 2015 as cited in Adams et al., 2015 p. 63) that paint “disability” as being undesirable, abnormal, and needing to be fixed characterize life with a disability as being isolating due to an inherent lack of belonging. This perception of disability as being a drastic and damning difference manifests in a variety of ways but ultimately leaves people with poor self-image, poor self-worth, and negatively impacted self-efficacy beliefs (Bandura, 1989, p. 1179). In turn this often results in individuals with disabilities distancing themselves from disability in the hopes that denying this part of their identity will foster a greater sense of mainstream belonging.
and subsequently higher self-esteem. The interviewees had different examples of how disability was avoided that were organized into four main sub themes: media portrayals, individuals with disabilities, resources about disability and for people with disabilities, and symbols of disability.

### Avoiding Disability During Adolescence

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<th>Interviewee</th>
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Table 1. Avoiding Disability During Adolescence

**Media portrayals.** Eight interviewees discussed how growing up with movies, television shows, sports events, and documentaries that portrayed disability as different was somewhat damaging to their self-image and autonomy (Haller et al., 2006; Young, 2014). The interviewees’ specific responses are summarized below in order to provide a succinct snapshot of their experience.

Interviewee 8 has a mild form of cerebral palsy, which results in reduced mobility that requires the use of crutches or a wheelchair. Growing up, Interviewee 8 watched television shows and movies that paired “disability” with pity, limited abilities, and being
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a token role. She realized at a young age that these television shows and movies were overcoming narratives, a genre of *inspiration porn* that frames individuals with disabilities as heroes merely because they tackle every day challenges. After seeing characters with visible disabilities being pitied and praised for dependency, Interviewee 8 refused to associate with “disability” and insisted on using her crutches and not her wheelchair. Even though using her wheelchair required less energy and was significantly more efficient, she thought it made her “look more disabled” and “pitiful.”

Interviewee 2 has a mental illness. As a young person he lived in a community and went to a school district that highly valued sports and athleticism. He was a dedicated athlete and felt that individuals with physical disabilities were not as strong and couldn’t play real sports. For example, when he saw the Special Olympics he felt that the athletes participated on such a low level that he didn’t consider them to be “real athletes.” Interviewee 2 struggled with his undiagnosed and untreated mental illness as a teenager but he thought that he was better off than most people with disabilities because there was nothing physically wrong with him. He recounts looking down on athletes with disabilities because they were not on the same level of athleticism as able-bodied people. Disability was not a part of his identity as a physically capable young man who from the outside looked “normal.”

Interviewee 6 has a covert stutter and was mute for five years. Growing up any depictions of people stuttering or references to stuttering made her feel overwhelmed, panicked, and embarrassed. Movies, television shows, and commercials that broached the subject of stuttering made her want to retreat further into her mutism and isolate herself from the speaking world. Interviewee 6 also explained that her stutter was both
emotionally and physically painful. When she would become anxious it felt like she was being choked and the sensation was incredibly overwhelming. Since Interviewee 6 did not know how to manage her stutter or even ask for help, watching any portrayal of stuttering was a significant trigger.

**Individuals with disabilities.** Six interviewees discussed how during their youth and young adulthood they tried to avoid other individuals with disabilities for fear that association would make them look “more disabled.” Most young people spend their adolescence desperately striving to be “normal” and fit in with their peers. The interviewees were no exception and during their youth they also pursued normalcy by making able-bodied and neurotypical friends and inclusion in mainstream activities. Belonging in mainstream society was envisioned as an incredible accomplishment. The interviewees described how fitting in with “normal” peers was causally linked to avoiding peers with disabilities. For example, being “looked upon as the guy in the wheelchair” (Interviewee 9) or labeled as “that disabled girl” (Interviewee 4) drove a distinct wedge between the interviewees and the able-bodied and neurotypical peers they wanted to build relationships with. As youth the interviewees worried that if they were perceived as too embedded in the disability community then their typical peers would make no effort to include them. Finally, stigma, stereotypes, and attitudinal barriers also impacted the interviewees, particularly those with invisible disabilities. Negative experiences with individuals with similar disabilities often resulted in delayed diagnoses and treatment because interviewees did not want to “come out,” fearing that doing so would result in discrimination and the same stigmatized fate. The interviewees’ specific
responses are summarized below in order to provide a succinct snap shot of their experience.

Interviewee 4 uses a motorized scooter and has medical disabilities and growing up, she refused to participate in disability activities like adapted sports and dance for fear of “looking more disabled.” Interviewee 4 spoke of not having many friends as a young person and being one of the few students with a visible disability in her rural school district. Interviewee 4 intentionally avoided other students with disabilities for fear of being associated with them. She attempted to fit in with the country culture favored by her classmates by listening to country music, wearing cowboy boots, and embracing her school’s rural identity even though she did not personally like those things. Interviewee 4 dedicated her time and energy towards pursuing an identity similar to that of her peers and refused to go to camps for teenagers with disabilities, declaring she was, “not like that!” For example, in order to help her fit in, Interviewee 4 and her mother founded a dog training club within 4-H since 4-H was very popular in her rural community.

However, despite being almost completely surrounded by able-bodied and neurotypical peers, Interviewee 4 stated that she felt incredibly isolated for most of her schooling.

Interviewee 2 has a mental illness and growing up he did not initially tell his parents about his symptoms because he associated mental illness with certain members of his family who were mentally ill and had violent tendencies. His desire to avoid a diagnosis and ignore his symptoms also stemmed from stigma rooted in ableism and racism. As a black man Interviewee 2 feared that if he was diagnosed as mentally ill he would face significantly more prejudice in his every day life as someone living with two marginalized identities. Interviewee 2 tried to manage his illness secretly but his
symptoms intensified due to lack of treatment. After a particularly severe episode he was hospitalized and formally diagnosed. Interviewee 2 stated that he viewed being diagnosed—confirming he in fact had an illness—as a sign of weakness. He explained that as a black man in America he must always exude strength in an attempt to undermine the power differential that comes from living in a racist society. Interviewee 2 told me that having a mental illness opens one up to an onslaught of stereotypes and prejudice that makes living in a predominantly white and neurotypical world all the more challenging. Therefore, for him as a youth, the diagnosis felt particularly condemning.

Interviewee 7 acquired a spinal cord injury at 15 and met other young people with similar injuries and similar mobility issues in the hospital. As a teenager Interviewee 7 became heavily involved in adaptive sports, where he played on teams with other individuals who had paraplegia. While Interviewee 7 did not avoid his teammates who used wheelchairs, he strongly differentiated between people who use wheelchairs like him and “other people with disabilities,” who he viewed as “more disabled.” As a teenager Interviewee 7 only associated with wheelchair users because he felt their level of disability was not as significant or limiting as other types of disabilities. When it came to interacting with individuals with other types of disabilities, Interviewee 7 shared that as a young adult he felt that they would have nothing in common.

Interviewee 9 uses a wheelchair and growing up he dedicated a lot of time and energy towards becoming popular and having able-bodied friends. He spoke of the three or four other students with visible disabilities in his school and how they lived in a “circle of disability.” He discussed how they were much more defined and limited by their disabilities while he challenged the stereotype surrounding disability by being popular,
having able-bodied friends, dating able-bodied girls, and “doing things that kids with disabilities aren’t supposed to do.” Interviewee 9 shared that upon entering high school he didn’t want to be bullied or ignored and since no one would recognize him as a “tough guy in a wheel chair” he made friends with as many people as possible. He had friends who played on all the sports teams, friends who were in student council, friends who worked on the school newspaper, and in the yearbook he was in 15 different pictures because he was involved in everything – “except disability.” Interviewee 9 shared that initially being popular was a survival technique in his tough high school but ultimately being fully included in every day life made him feel upwardly mobile, successful, and not restricted by a limiting disability stereotype.

**Resources about disability and resources for people with disabilities.** Five interviewees spoke about their refusal and reluctance to: learn about their disabilities, learn about the disability community and disability culture, and use accommodations. For many young adults with disabilities the decision-making process regarding accommodations is rather nuanced. While many adolescents with disabilities are introduced to the accommodation process as students in public school through the provision of IEPs and 504 plans, the implementation of accommodations is not always guaranteed. School systems can fall short when it comes to providing accommodations and sometimes students do not pursue setting up their plans or holding the school accountable (Scholl and Mooney, 2004).

For many youth who struggle with understanding and accepting their disability, the decision to use accommodations is often interpreted as admitting you are different. Students are presented with the option to claim their disability and be eligible for
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accommodations or distance themselves from having a disability-identity, which renders them ineligible for accommodations that could substantially help them as learners (Scholl and Mooney, 2004). It is important to note that this accommodation paradox is salient not only in classrooms but in other settings where disclosure is necessary before reasonable accommodations or equitable access is provided, such as in employment. Interviewees shared stressful experiences not using accommodations and subsequently outlined the decision making process that led them to learn more about their disability, disclose their disability and publically use accommodations, and find community. The interviewees’ specific responses are summarized below in order to provide a succinct snap shot of their experience.

Interviewee 8’s previous career was working in fundraising and whenever she would apply for jobs she did this independently of any disability related resources or assistance. Interviewee 8 was adamant about not including her disability in job searches and even more so not requesting on the job accommodations. Her rationalization was that she was “not that disabled” and didn’t need them. After Interviewee 8 was let go from a job she realized that she was in the wrong field but was unsure how to take the next step in finding a new career. Despite her trepidation she decided to go to a job fair for individuals with disabilities that would undeniably “out her as disabled” but connect her with potentially useful resources. Interviewee 8 was able to find a new job in a field she feels better suited for and attending the job fair also challenged some of her attitudinal barriers regarding her disability. Through this experience Interviewee 8 learned about different types of accommodations that she is eligible for that actually meet her needs, like a discounted bus pass. This reclamation of her disability also led to her formally
certifying her disability status through the federal government so if she is ever unemployed she will have some legal protections.

Interviewee 10 was diagnosed with spina bifida as a baby. Spina bifida, a birth defect that results in an underdeveloped spinal cord, impacts people very differently and in Interviewee 10’s case it mostly impacts her mobility. Interviewee 10 grew up attending summer camps with other youth with spina bifida who had more profound needs. Despite the fact that Interviewee 10 has more advanced skills she found that staff at these summer programs routinely lumped her into the same category as other campers and in doing so ignored her individual needs. While there were times Interviewee 10 enjoyed attending summer camps and after school programs, many of these experiences were frustrating because she was higher functioning then many of the other youth. Interviewee 10 found herself pulling away from disability based programs because she was not treated like her own person. In her mind, attending the camp meant forfeiting her unique identity because she was categorized as “just another camper.”

Symbols of disability. Six interviewees shared stories about their relationship with symbols of disabilities while growing up. The category “symbols of disabilities” refers to objects, people, and anything the individual perceived as being a marker of disability that negatively impacted their identity. The interviewees spoke of these often-inescapable markers like scarlet letters. They were framed as undesirable accessories that interviewees would try to remove and distance themselves from to put space between themselves and disability. The interviewees explained that reliance on and association with these symbols confirmed disability status, reiterated the existence of an isolating difference, and reinforced disability stereotypes especially in regard to dependence. The
interviewees’ specific responses are summarized below in order to provide a succinct snapshot of their experience.

Interviewee 4 uses a motorized scooter and frequently requires medical care. Growing up she both opted for and created “disability free” spaces. These spaces were not traditionally associated with disability; for example she participated in a 4-H program doing dog training, an activity that she was able to do with her disability, yet 4-H is not reserved for youth with disabilities. In addition to finding or making disability free spaces, Interviewee 4 would distance herself from symbols of disability. In middle and high school Interviewee 4 routinely left her wheelchair in the hall during classes and would ask her nurse to stay in a classroom closet so having a nurse was less obvious. Interviewee 4 told me that during her school years everything she did was an effort to look less disabled. In order to minimize how different she looked from her peers she distanced herself from anything and everything that made her disability obvious and more significant.

Interviewee 5 (who uses identity first language) is autistic and during her interview she explained how growing up, she was able to pass as neurotypical because she figured out the social rules guiding behavioral expectations for women. For example, instead of stimming by shaking her hands she would twist a ring on her finger or a strand of hair, which is viewed as being feminine, not as autistic. Cognizant of social rules and societal expectations for femininity, Interviewee 5 started scheduling her self-care activities to revolve around neurotypical expectations, i.e. getting her nails done. She shared that it is resoundingly easier to navigate a very binary world by adopting one set of social rules and expectations that she can adhere to. Interviewee 5 elaborated that this
means shaving her legs, getting her nails done, and dressing well among other things that allow her to safely exist in the “feminine box.” While she of course has other interests, presenting herself to the world in a markedly feminine way allows her to exist within society’s standards much more easily. For Interviewee 5, successfully passing as a typecast woman affords her the opportunity to belong and fit as well as makes her experience living in a heteronormative, patriarchal culture much safer. Interviewee 5’s story exemplifies how actions levied to fit in were not always focused on avoiding symbols of disability but could also be centered on adopting and incorporating “normal” behaviors and “normal” identifiers in every day mannerisms to pass in very prescribed social contexts.

**Outlier.** Finally, I must discuss Interviewee 1, whose experience growing up with a disability was markedly different than the other interviewees. Interviewee 1 did not share any memories or stories about avoiding disability in the media, distancing herself from other people with disabilities, avoiding disability resources, or distancing herself from symbols of disability. Out of all of the interviewees, Interviewee 1 was the only one to talk about her faith. Interviewee 1 discussed how her faith is a significant guiding force in her life and she stated several times that God will help her reach her goals; “I’m a big believer in God. He wouldn’t have given me this idea [her desire to build an accessible waterpark] if he wouldn’t help me make things happen.” Interviewee 1 described her childhood as one spent frequenting waterparks with her family, being involved in horseback riding and sports, and living in a conservative, religious town where believing in God brought the community together. While all of the other interviewees discussed the ongoing strain of growing up with a disability that negatively
impacted their self-esteem and sense of belonging due to an ableist culture, Interviewee 1’s narrative replaced those sentiments instead with expressions of faith. It appears that Interviewee 1 avoided dwelling on the negative reality of living with a disability by focusing her energy and insights on her strong religious conviction. Instead of addressing the structural inequities of an ableist system, Interviewee 1 focused her attention on God’s ability to provide for her and others in need – disabled or not. As an adolescent, Interviewee 1’s faith made disability a matter of God’s providence and not a social construct.

**Epiphanic Experiences**

The theme “Avoiding Disability” described a period in the interviewees’ lives when having a disability meant being different, excluded, and objectified. Thus, disability was avoided at all cost. However, eventually disability was no longer avoided and the interviewee was able to move forward in an ableist world, a transition I attribute to an “epiphanic experience.” I labeled these experiences “epiphanic experiences” because the interviewees described how these experiences forced them to challenge how they thought about themselves and their relationship with disability. Epiphanic experiences were byproducts of both positive and negative circumstances that created space for introspection, renewed self-image, and afforded the interviewee an opportunity to scrutinize how society understands and treats disability. These experiences resulted in the realization that society frames disability as a “disabling difference” and from that realization interviewees began redefining their own identities as individuals who could both articulate their aspirations and make plans to achieve them.
Epiphanic experiences encapsulate the process of pushing back on stigma to redefine ability, which is a vital stage in reclaiming identity and practicing self-determination (Peters, 1999 as cited in Haller et al., 2006). Epiphanic experiences ultimately asked the interviewees to answer the following questions: “Who am I?” and “What do I want to do?” Within the context of accumulated experiences, relationships, authentic learning opportunities, and the maturation of self-perceptions, interviewees were able to use these epiphanic experiences to construct intentional identities that explored disability, identity, agency, and goals. These epiphanic experiences also served as a call to action—the tipping point that informed the interviewees’ next steps, creating tangible plans as they moved towards adulthood and developed as individuals.

Epiphanic experiences are undergirded by the principles of Bandura’s social cognitive theory (2001) as they encourage the individual to dedicate time to defining the self, defining values, setting goals, and exercising agency. Ultimately, epiphanic experiences are opportunities for insight and action. The epiphanic experiences in this study were defined by the following sub themes: epiphanic experiences from negative events, epiphanic experiences from social issues, epiphanic experiences from attending disability conferences, and epiphanic experiences from healthy relationships. The interviewees’ specific responses are summarized per sub theme in order to provide a succinct snap shot of their experience.
Epiphanic experiences derived from negative events. Interviewees 1 and 2 were set apart because they discussed their epiphanic experiences as being the result of negative events. Interviewee 1, who uses a wheelchair, first experienced the limitations that came with disability when she was 13 and could no longer access water slides. As an avid water park enthusiast, Interviewee 1’s father would carry her up the steps of water slides and then meet her at the bottom with her wheelchair. However, eventually Interviewee 1 got too tall and too heavy and her father could no longer carry her up water slide steps. Interviewee 1 recounted how this epiphanic experience was devastating and still painful to remember because it was the first time she realized that the world is an unfair place. After this experience, Interviewee 1 pledged to build an inclusive and integrated water park for people with disabilities—a goal she still has today.
Interviewee 2 has a mental illness and as a teenager he tried to hide his symptoms and manage his illness on his own, fearing the stigma of a diagnosis. Unfortunately he became increasingly symptomatic and this resulted in an involuntary hospitalization. This hospitalization served as his epiphanic experience. While Interviewee 2’s stay in the psychiatric unit ultimately gave him insight into his illness and resources to help him manage it, he recounts the experience as being extremely negative. Interviewee 2 stated that being physically constrained in an environment, like a hospital, does “unforgettable things to you” as you lack rights and control. After this epiphanic experience and release, Interviewee 2 was able to apply a behavioral management strategy that he learned while inpatient that enabled him to build structure and routine into his every day life. This behavior modification provided Interviewee 2 a more secure sense of control that resulted in fewer and less severe episodes, which has also meant less time spent in the hospital. Interviewee 2’s epiphanic experience made him face the reality that he does have a mental illness but if he manages it he can live his own life on his own terms.

**Epiphanic experiences derived from social issues.** Interviewees 3 and 5 are both autistic (and use identity first language) and they discussed how living with an invisible disability came with a unique set of challenges, especially when it comes to unwritten social rules and neurodiversity. For both Interviewees 3 and 5, their epiphanic experiences were preceded by noticeable difficulty conforming to a standardized social system. Upon recognizing that they were struggling with relationships and societal expectations, the interviewees actively turned towards finding an explanation for this difficulty and subsequently received an autism diagnosis.
Interviewee 3 recounted that they knew they were different starting in their early teens but due to stigma they were never assessed for autism; their parents and teachers wanted to “protect them from the label.” Interviewee 3’s epiphanic moment sparked during their senior year of college when they were trying to complete their field experience for their Bachelor’s degree in social work. During this intensive field experience, their professors told them that they didn’t have the social skills necessary to become even an entry-level social worker. Interviewee 3 was labeled as “lazy” and “entitled” when in reality their struggles stemmed from undiagnosed autism. After this epiphanic experience Interviewee 3, knowing full well that they weren’t lazy or entitled but clearly different, decided to get formally diagnosed and come out as autistic. An autism diagnosis made Interviewee 3 eligible for accommodations in their master’s program that have optimized their chances at success. Interviewee 3 reflected that not having a diagnosis was actually more isolating and limiting than having one because diagnoses are the first step in learning ways to manage a condition and talk to others about differences. Interviewee 3 is now an outspoken autistic advocate.

Interviewee 5 is autistic and she also was not diagnosed until college. While she always knew she was different she did not seriously question these feelings since she was smart and able to navigate life effectively. Interviewee 5’s epiphanic moment sparked when her college boyfriend cheated on her. Interviewee 5 stated that this was the first time she had ever been lied to and realized that people can and do lie. Interviewee 5 explained that after this devastating violation of trust she was forced to assess her ability to read and understand social cues and ultimately decided to pursue an autism diagnosis. Interviewee 5 stated that being diagnosed was affirming because it gave her an
explanation, a community, and the opportunity to start addressing her neurodivergence in a neurotypical world. Interviewee 5 spoke at length about how she has learned the unwritten social rules for a variety of contexts and how she has worked incredibly hard to be successful in a multitude of social roles. She articulated that following social rules is vital because if you do not fit in in social contexts you are liable to be taken advantage of and disempowered. Interviewee 5 concluded that her goals are to do policy work and lobby for disability issues, which necessitates being able to do things people with autism “aren’t supposed to know how to do,” like manipulation. Interviewee 5 articulated how she is a very capable policy advocate and autistic advocate.

**Epiphanic experiences derived from attending disability conferences.**

Interviewees 4 and 7 have visible disabilities and they are wheelchair users. During their interviews they both discussed how attending a conference organized by individuals with disabilities, for individuals with disabilities, expanded how they defined disability on a personal level as well as their perception of how disability fits in an able-bodied, neurotypical world.

Interviewee 4 grew up in a rural area and did not have many peers with disabilities. As a teenager most of the people she met who had similar disabilities were older adults who she could not relate to. Interviewee 4 never perceived disability as something she could be proud of; it was purely a medical condition that needed to be fixed. Her parents suggested that she meet peers with disabilities, knowing that she could learn from them something no textbook or medical professional could teach her, but she was hesitant for many years. When Interviewee 4 was 18 her mother finally convinced her to attend a national youth leadership conference where for the first time she met “cool
young people with disabilities.” She said that she does not remember the conference theme or any of the speakers, only the other youth she met and befriended. Interviewee 4 explained that the relationships she cultivated at the conference changed her life. Interviewee 4 shared that this epiphanic experience helped her redefine her disability-identity, boosted her confidence and disability pride, and gave her a sense of purpose. After the conference Interviewee 4, who had originally hoped to become a veterinarian, completely switched her focus and dedicated her life’s work to working in disability and youth leadership.

Interviewee 7 acquired a spinal cord injury at 15 and he learned about “disability” during his emergency treatment, subsequent hospital stays, and later through his involvement in wheelchair athletics. Interviewee 7’s only friends with disabilities were his teammates and due to limited experiences with individuals with other types of disabilities he strongly differentiated between people who used wheelchairs like him and “other people with disabilities,” who he viewed as more disabled. Interviewee 7 discussed how growing up he did not have a disability-identity because he did not interact with the disability community, only other wheelchair users. However, as a young adult, Interviewee 7 attended a cross-disability Independent Living Movement conference and for the first time he saw disability as an actual, distinct community. He realized that individuals with disabilities are connected and share many commonalties, including challenging stereotypes, experiencing disability oppression, and advocating for equitable access. Interviewee 7 explained how this conference opened his eyes to see the authentic, inclusive, and impactful disability community that is powerful, progressive, and diverse.
Interviewee 7 described this day as being one of the best days of his life because it made him decide to work in the disability field.

**Epiphanic experiences derived from healthy relationships.** Interviewees 6, 8, 9, and 10 discussed the significance that healthy relationships played in their development as confident, self-determined young adults. For these interviewees cultivating friendships, growing in safe spaces, and watching their actions come to fruition solidified their identities as decision makers with an internal locus of control. As Bandura (2001) argued, the ability of a person to cause change is inextricably linked to their perception that they have the power to make the desired change a reality. In Interviewee 6, 8, 9, and 10’s narratives they described how their relationship-driven epiphanic experiences fostered opportunities to reclaim their disability-identities and expand their capacities for self-efficacy. In other words, forging positive, healthy relationships empowered the interviewees to see themselves as positive, healthy forces.

Interviewee 6 had never found a safe space to talk about her stutter until after college when she got her first job working in a hospital. Growing up, Interviewee 6 never experienced her family broaching the subject of her stutter or her selective mutism and she was reluctant to ask for help as her parents emphasized the importance of being independent. During college, Interviewee 6 was too intimidated to ask for help and she was able to finish her degree without addressing her stutter. Interviewee 6 had always hoped that her stutter would go away if she avoided it but intellectually she knew that was improbable. Interviewee 6 took the hospital job thinking it wouldn’t have any impact on her stutter so she was quite surprised to find that this job turned out to be an empowering, epiphanic experience. While previously Interviewee 6 had had negative
experiences with the health care system, in this new role her coworkers, competent and compassionate clinicians, helped her learn more about her stutter, recommended speech therapists, and supported her to do things that “people with stutters just don’t do,” like answer the phone at work. For Interviewee 6 working at the hospital with the support of knowledgeable and approachable health care professionals gave her the confidence to develop her skills as a professional in her own right and enabled her to ask for help when she needs it.

Interviewee 8 struggled to develop a positive disability-identity growing up because she did not have many peers with disabilities. She also recounted how media depictions of disability were patronizing and objectifying and these negative portrayals left her feeling embarrassed and isolated. Interviewee 8 explained how it was really hard for her to build a better self-image without any friends or role models who mirrored her experience. In fact, Interviewee 8, who has a mild form of cerebral palsy, assumed that she would never fit in with able-bodied peers or peers with cerebral palsy because the majority of people she met with cerebral palsy had more significant needs.

However, when Interviewee 8 went to college she met many students with disabilities and the camaraderie born of the shared disability experience made her question what disability truly means. In addition these friendships were not centered solely on disability. Looking back, Interviewee 8 reflected that she had the typical college experience that she had always desired within the supportive scaffolding of a likeminded group of peers. Interviewee 8’s relationship with this tightknit group of friends nurtured her development as a disability advocate and activist as well as helped her reclaim how disability impacts her identity. Instead of her disability being a segregating and limiting
factor, it enabled her to establish healthy friendships and develop her own authentic
disability-identity that provided direction and helped her attain fulfillment. For
Interviewee 8, her epiphanic experience was finding peers who reflected back to her the
idea that living with a disability did not preclude someone from living a normal,
satisfying life.

Interviewee 9, who uses a wheelchair, attended a tough high school and in order
to avoid being bullied or excluded he deliberately made friends with everyone.
Interviewee 9 explained that he has always been good with people and starting in high
school he learned how to relate to different audiences so he would always fit in wherever
he went. He became popular because he had friends spanning different high school
cliques, extra curricular activities, and sports teams. As discussed earlier, Interviewee 9
was able to forge an identity outside of disability because no one perceived him as being
the stereotypical “kid in the wheelchair.” Interviewee 9 reflected that his decision to
become popular and the fact he accomplished this goal was a pivotal, epiphanic
experience because he learned that with dedicated effort he could carve out his own
agentic identity.

During the interview, Interviewee 9 shared his extensive history as a professional
and as an advocate, declaring that forging a strong sense of self-efficaciousness
empowered him to tackle his goals. Interviewee 9 told me that he is determined to
continue giving back to his community and one way this has taken shape is through
motivational speaking gigs across the country. Interviewee 9 reports that through these
events he has helped nurture a new generation of disability advocates. Reflecting on this
success, Interviewee 9 announced that he has decided to shift his focus from youth with
disabilities to working with able-bodied, neurotypical youth in order to challenge misconceptions about disability from a different perspective. Interviewee 9 articulated that he is looking forward to growing disability acceptance and increasing understanding by expanding his target audience. Interviewee 9 shared that he is confident in his ability to reach able-bodied, neurotypical audiences because his skill set has only strengthened over the years. Interviewee 9 describes himself as a seasoned public speaker who can easily engage with, connect, and impact diverse audiences via sharing his personal experiences, outlining lessons learned, utilizing his sense of humor, and channeling his charismatic energy. Throughout the interview Interviewee 9 openly embraced the effectiveness of his talents, strengths, work ethic, and his conviction to make a difference, at one point saying that “it is always about the hustle.”

Interviewee 10 shared that during her childhood and adolescence most of her peers did not include her in everyday activities. Interviewee 10, who used crutches as a child and later a motorized scooter, stated that the major issue for her classmates was that she could not physically keep up. Interviewee 10 explained that this was both hurtful and frustrating, especially considering her classmates never took the time to get to know her, instead relying on disability stereotypes. Interviewee 10 elaborated further, detailing how both her peers and teachers were dismissive of her capabilities and encouraged her to set easier goals. They relied on her diagnosis to sum up her abilities and predict her achievements. Interviewee 10 felt incredibly isolated until she began playing adapted lacrosse. Being part of a cohesive team afforded Interviewee 10 the opportunity to educate her teammates about disability and in doing so develop as an advocate. Interviewee 10 stated that playing on the team provided a way to make friends and the
entire team learned the value of communication and patience, and recognized that everyone has the ability to contribute on a team, albeit in different ways. Interviewee 10 said that playing on the lacrosse team, her epiphanic experience, allowed her to develop her own unique identity – not just the girl with the crutches. For Interviewee 10 this opportunity to be part of a team instilled the belief that we all have something to offer, we all need to decide who we are and what we want, and being true to you is paramount. Interviewee 10 is working on her master’s degree with a focus on community advocacy.

**The self, society, and epiphanic experiences.** Epiphanic experiences serve as catalysts for self-discovery and self-development. The interviewees took advantage of these self-identified learning opportunities to assess their self-perceptions as well as how the world perceives them. Acknowledging that “disability” is often viewed as being less-than, interviewees identified epiphanic experiences as fostering opportunities to reexamine societal expectations, redefine their own identities, establish their own goals, and author their own understanding of “disability.” Throughout this growth, epiphanic experiences positioned the interviewees to engage in the narrative process and reap the associated benefits (Bandura, 1989, 2001; Pennebaker, 1999, 2006; Wilson, 2004). The interviewees, who are successful young professionals with disabilities, shared rich narratives in which epiphanic experiences motivated them to cultivate their own disability-identity, their own understanding of agency, and establish their own goals. By answering the two questions posed by epiphanic experiences, “Who am I?” and “What do I want to do?” the interviewees were able to move forward as purposeful and accomplished adults.
Establishing Goals and Roles

For the interviewees, epiphanic experiences signaled a shift in consciousness in which they began to challenge their perceptions of disability and capacity for agency. The interviewees discussed how their epiphanic experiences led to the development of a more intentional identity, an individual who could bring about the change they desired. As postulated by Bandura (2001), the goals an individual sets reflect how they see themselves, as someone who is capable of authentic achievement or as someone mired in the confines of low expectations. These goals not only indicate the individual’s perception of their self-efficacy but also mirror their values and priorities (Bandura, 2001). Bandura (1989) found that individuals with low self-efficacy were far more likely to limit professional and educational options simply based on perceived shortcomings in their own causality and not their actual performance deficits. Overall the interviewees viewed their epiphanic experiences as necessary hurdles that spurred a declaration of identity as framed by establishing meaningful goals and roles. Again, the epiphanic experiences resulted in insight and action.

During the interviews each interviewee talked openly about their strengths and readily shared stories of their accomplishments. The interviewees framed their identities and social roles as effective agents and successful advocates who are able to direct their actions due to a well-established set of values, which are reinforced by a cogent sense of purpose. The interviewees described this cognitive cycle and associated actions as a feedback loop. At the core was their self-derived identity, a product of epiphanic experiences, learning opportunities, and decision-making, which is influenced by the
integrated elements of the interviewee’s goal-oriented trajectory: values, purpose, skills, accomplishments, and action plans.

The tables below contain synthesized data for each interviewee, listing their respective epiphanic experience and its translation into self-defined goals and roles.
### Establishing Goals and Roles

#### Interviewee 1
**Epiphanic Moment: Inaccessible water slides**

| Values          | Accessible opportunities  
| An            | Fairness                  
|               | Faith                     |
| Purpose        | Build an accessible water park and employ individuals with disabilities |
| Skills         | Social media              
| An            | Mechanical engineering   |
| Accomplishments| Bachelor’s and Master’s degree |
| An            | Independence              
|               | Escaped conservative hometown |
| Action Plan   | Attain ADA coordinator certification |
| An            | Reach out to water park development companies and conduct a feasibility study |
| An            | Network                   |

Table 3. Epiphanic Moment for Interviewee 1

#### Interviewee 2
**Epiphanic Moment: Hospitalization**

| Values          | Social justice                  
| An            | Equity                        
|               | Moral compass                  
|               | Integrity                      |
| Purpose        | Dismantle systems of oppression |
| An            | Intersection of race and disability/mental illness |
| Skills         | Advocacy                       
| An            | Discipline                     
|               | Social consciousness            |
|               | Reflection                     
|               | Community organizing           |
| Accomplishments| Director at a non-profit       |
| An            | Healthy for two years          
|               | Visible in the disability and black community |
| Action Plan   | Utilize peer model             |
| An            | Challenge white privilege in the disability community and the disability hierarchy |
|               | Address racism’s reflection in ableism and sexism |

Table 4. Epiphanic Moment for Interviewee 2
### Establishing Goals and Roles

**Interviewee 3**  
**Epiphanic Moment:** Academic problem due to social skills issues

<table>
<thead>
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<th>Values</th>
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<tbody>
<tr>
<td></td>
<td>Inclusion and integration</td>
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<td></td>
<td>Space for togetherness</td>
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<td></td>
<td>Diversity</td>
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<td>Identity pride</td>
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<table>
<thead>
<tr>
<th>Purpose</th>
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<tbody>
<tr>
<td></td>
<td>Dismantle pathology paradigm</td>
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<tr>
<td></td>
<td>Coalesce queer/LGBTQA community, intersectional feminism, autism, and neurodiversity into definition of disability</td>
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<td></td>
<td>Visibility</td>
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<tr>
<th>Skills</th>
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<tbody>
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<td></td>
<td>Community and legislative advocacy</td>
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<tr>
<td></td>
<td>Applying peer model</td>
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<tr>
<td></td>
<td>Connector</td>
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<tr>
<th>Accomplishments</th>
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<tbody>
<tr>
<td></td>
<td>Bachelor's degree</td>
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<td></td>
<td>Left hometown</td>
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<tr>
<td></td>
<td>Forged partnership between queer community and autistic community</td>
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<td></td>
<td>Founded two autistic advocacy and support groups</td>
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<tr>
<th>Action Plan</th>
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<tbody>
<tr>
<td></td>
<td>Starting Master's program</td>
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<td></td>
<td>Expand peer model</td>
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<tr>
<td></td>
<td>Expand ally network</td>
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<tr>
<td></td>
<td>Attain non-profit status for newest autistic advocacy and support group</td>
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Table 5. Epiphanic Moment for Interviewee 3

### Establishing Goals and Roles

**Interviewee 4**  
**Epiphanic Moment:** National leadership conference for youth with disabilities

<table>
<thead>
<tr>
<th>Values</th>
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<tbody>
<tr>
<td></td>
<td>Universal acceptance</td>
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<tr>
<td></td>
<td>Belonging</td>
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<td></td>
<td>Youth development</td>
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<td>Identity pride</td>
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<table>
<thead>
<tr>
<th>Purpose</th>
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<tbody>
<tr>
<td></td>
<td>Be needed</td>
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<tr>
<td></td>
<td>Make opportunities for others</td>
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<td></td>
<td>Youth leadership</td>
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<td>Visibility</td>
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<tr>
<th>Skills</th>
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<tr>
<td></td>
<td>Independence and stick-to-tiveness</td>
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<td></td>
<td>Applying peer model</td>
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<td></td>
<td>Advocacy</td>
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<td></td>
<td>Community organizing</td>
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<tr>
<th>Accomplishments</th>
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<tbody>
<tr>
<td></td>
<td>Extensive resume and awards</td>
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<td></td>
<td>Founded several youth leadership groups (local and statewide)</td>
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<td></td>
<td>Bachelor's, Master's, and Doctoral degree</td>
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<td></td>
<td>Statewide policy changes</td>
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<table>
<thead>
<tr>
<th>Action Plan</th>
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<tr>
<td></td>
<td>Legislative advocacy</td>
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<td></td>
<td>Work internationally on disability issues</td>
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<td></td>
<td>She is approached with job opportunities</td>
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<td>Visibility</td>
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</table>

Table 6. Epiphanic Moment for Interviewee 4
## Establishing Goals and Roles

### Interviewee 5

**Epiphanic Moment: Violation of trust and social skills issues**

| Values       | Access and accessibility  |
|             | Equity                    |
|             | Representation             |
|             | Integrity and authenticity|
|             | Identity pride            |

| Purpose      | Document disability narratives regarding interpretation of access |
|             | Reclaim power            |
|             | Strengthen and apply political savviness |
|             | Advocacy                 |

| Skills       | Diligence, productivity, and stick-to-liveness |
|             | Community and legislative advocacy |
|             | Making disability work for her |

| Accomplishments | Bachelor’s and Master’s degree |
|                 | Helped found two autistic advocacy and support groups |
|                 | Knows the necessary social rules to surpass expectations in multiple roles/social contexts (advocate, partner, doctoral student, activist) |

| Action Plan   | Explore ever-changing social rules |
|               | Enrolled in doctoral program |
|               | Autistic advocacy through non-profit group, political efforts, and doctoral work |
|               | Viability |

Table 7. Epiphanic Moment for Interviewee 5

## Establishing Goals and Roles

### Interviewee 6

**Epiphanic Moment: Job at a hospital**

| Values       | Opportunity |
|             | Equity      |
|             | Safe spaces |
|             | Education   |
|             | Belonging   |

| Purpose      | Help friends, colleagues, and community |
|             | Nurture    |
|             | Connect individuals and resources |

| Skills       | Courage and willingness to try Communication Self-awareness and mindfulness |

| Accomplishments | Bachelor’s and Master’s degree |
|                 | Established healthy relationships |
|                 | Practices good self-care |
|                 | A visible resource in the community |

| Action Plan   | Advocate in personal and professional life |
|               | Create safe spaces for vulnerable populations |
|               | Maintain self-care and balance |

Table 8. Epiphanic Moment for Interviewee 6
## Establishing Goals and Roles

<table>
<thead>
<tr>
<th>Interviewee 7</th>
<th>Epiphanic Moment: Cross-disability independent living conference</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Values</strong></td>
<td>Importance of community&lt;br&gt;Integration&lt;br&gt;Individual and community access&lt;br&gt;Responsibility</td>
</tr>
<tr>
<td><strong>Purpose</strong></td>
<td>Bring visibility to disability&lt;br&gt;Help individuals with disabilities work in disability fields, especially hold roles in upper management&lt;br&gt;Possion and accountability</td>
</tr>
<tr>
<td><strong>Skills</strong></td>
<td>Community and legislative advocacy&lt;br&gt;Leader&lt;br&gt;Systems advocate (college, independent living, health care)</td>
</tr>
<tr>
<td><strong>Accomplishments</strong></td>
<td>Highly visible&lt;br&gt;Established reputation in advocacy work locally and nationally&lt;br&gt;Bachelor's degree</td>
</tr>
<tr>
<td><strong>Action Plan</strong></td>
<td>Apply for Master's program&lt;br&gt;Inclusive athletics center for disability and able-bodied communities&lt;br&gt;Legislative work - identify and fix issues</td>
</tr>
</tbody>
</table>

Table 9. Epiphanic Moment for Interviewee 7

## Establishing Goals and Roles

<table>
<thead>
<tr>
<th>Interviewee 8</th>
<th>Epiphanic Moment: College friends with physical disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Values</strong></td>
<td>Authenticity (self and relationships)&lt;br&gt;Integration&lt;br&gt;Education</td>
</tr>
<tr>
<td><strong>Purpose</strong></td>
<td>Helping people&lt;br&gt;Living authentically&lt;br&gt;Visibility</td>
</tr>
<tr>
<td><strong>Skills</strong></td>
<td>Communication&lt;br&gt;Advocacy&lt;br&gt;Independence&lt;br&gt;Resilience</td>
</tr>
<tr>
<td><strong>Accomplishments</strong></td>
<td>Bachelor's degree&lt;br&gt;Fulfillment&lt;br&gt;Reclaimed identity</td>
</tr>
<tr>
<td><strong>Action Plan</strong></td>
<td>Resource for others (personally and professionally)&lt;br&gt;Staying involved in the disability community&lt;br&gt;Self-reflection&lt;br&gt;Being a good friend</td>
</tr>
</tbody>
</table>

Table 10. Epiphanic Moment for Interviewee 8
### Establishing Goals and Roles

#### Interviewee 9

**Epiphanic Moment: Popularity in high school**

<table>
<thead>
<tr>
<th>Values</th>
<th>Belonging</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Opportunity</td>
</tr>
<tr>
<td></td>
<td>Giving back</td>
</tr>
<tr>
<td></td>
<td>Education</td>
</tr>
<tr>
<td></td>
<td>Passion and positivity</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Purpose</th>
<th>Advocacy amongst youth of all abilities</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Efforts to improve the region</td>
</tr>
<tr>
<td></td>
<td>Leadership and mentorship</td>
</tr>
<tr>
<td></td>
<td>Visibility</td>
</tr>
<tr>
<td></td>
<td>Intersection of disability and race</td>
</tr>
<tr>
<td></td>
<td>Take chances</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Skills</th>
<th>Working with people (leadership, charisma)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Seeing the big picture</td>
</tr>
<tr>
<td></td>
<td>Influencer - networking</td>
</tr>
<tr>
<td></td>
<td>Creativity</td>
</tr>
<tr>
<td></td>
<td>Work ethic</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Accomplishments</th>
<th>Serves on numerous boards and speaks at conferences</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Focus on self-betterment</td>
</tr>
<tr>
<td></td>
<td>Bringing disability into other conversations that don't typically incorporate disability issues</td>
</tr>
<tr>
<td></td>
<td>Bachelor's and Master's degree</td>
</tr>
<tr>
<td></td>
<td>The ability to touch lives - reach diverse audiences</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Action Plan</th>
<th>Education, outreach, and authentic storytelling through advocacy non-profit (he helped found)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Establish healthy boundaries</td>
</tr>
<tr>
<td></td>
<td>Focus on working with able-bodied, neurotypical youth about disability acceptance and inclusion</td>
</tr>
</tbody>
</table>

Table 11. Epiphanic Moment for Interviewee 9

### Establishing Goals and Roles

#### Interviewee 10

**Epiphanic Moment: Playing on the lacrosse team**

<table>
<thead>
<tr>
<th>Values</th>
<th>Autonomy</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Equality</td>
</tr>
<tr>
<td></td>
<td>Teamwork</td>
</tr>
<tr>
<td></td>
<td>Respecting individuality</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Purpose</th>
<th>Educating professionals and youth with disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Resource for professionals and youth with disabilities</td>
</tr>
<tr>
<td></td>
<td>Take chances</td>
</tr>
<tr>
<td></td>
<td>Visibility</td>
</tr>
<tr>
<td></td>
<td>Advocate</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Skills</th>
<th>Advocacy</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Communication</td>
</tr>
<tr>
<td></td>
<td>Independence</td>
</tr>
<tr>
<td></td>
<td>Stick-to-tiveness</td>
</tr>
<tr>
<td></td>
<td>Resilience</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Accomplishments</th>
<th>Academics (high school, Bachelor's degree, and enrolled in Master's program)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Reputation as an advocate</td>
</tr>
<tr>
<td></td>
<td>Supporting disability community and individuals with disabilities via work in health care</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Action Plan</th>
<th>Enrolled in Master's program</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Asked to serve on executive board for advocacy and public policy for a disability centered non-profit</td>
</tr>
<tr>
<td></td>
<td>Advocacy role in different settings (health care, college, non-profit sector)</td>
</tr>
</tbody>
</table>

Table 12. Epiphanic Moment for Interviewee 10
While, predictably, the interviewees had different skills, accomplishments, and action plans, when it came to discussing their values and overall sense of purpose there were many similarities. Considering all of the interviewees described themselves as disability advocates it was therefore foreseeable that they would have shared principles and a common language to discuss their mission. The four sub themes found within each interviewee’s narrative were: low expectations, giving back, living beyond the stereotype, and bringing visibility to disability.

**Low expectations.** Each interviewee was quick to point out that society has low expectations for individuals with disabilities, citing both personal and generalized examples of ableism. To quote Interviewee 9, “I never wanted to be a ‘successful person with a disability,’ I just wanted to be a successful person. The standards for disability are so low – many would say that I ‘made it’ by just graduating from high school.” Interviewee 8 shared that, “The worst part about having a disability is that people impose their own expectations on you.” The interviewees elaborated on the phenomenon of imposed low expectations as they discussed how the cultural concept of “disability” is based on stereotypes, misinformation, and an inauthentic definition of disability versus ability. The interviewees explained that the canned “disability narrative” used by dominant culture to discuss disability in relation to societal access, integration, and provision of equal rights is typically not told by someone living with a disability but rather a service provider, parent, medical professional, educator, etc. Interviewee 5 shared that she felt compelled to come out as autistic during her Master’s program in order to critique how there are not enough individuals with disabilities represented in academia and scholarship. Similarly, Interviewee 4 recognized the lack of youth experience and
youth voice reflected in services created for youth with disabilities by Pennsylvania’s Department of Education, so she successfully advocated to serve on advisory boards. As successful young professionals, the interviewees stated that it was critical for their stories, especially their successes, to be magnified in order to start reclaiming our cultural narrative of disability. All of the interviewees emphasized that rewriting dominant culture’s disability narrative is important to them as individual advocates with personal legacies and it is also an important part of giving back to the disability community.

**Giving back.** Giving back to the local disability community, to specific individuals, and supporting regional efforts was considered a priority by every interviewee. There was a diverse number of responses when it came to sharing how giving back manifested in each interviewee's life. Interviewee 7 explained that his personal mission is to mentor individuals with disabilities in order to ensure that individuals with disability will always be represented in places of employment. He posed the following question: “while there will always be a disability community, WHO in the disability community is going to staff our non-profits when there isn’t even enough disability awareness in people with disabilities?” Interviewee 6 shared that not many adult women have a stutter and during her involvement with the National Stuttering Association (NSA) she only met three women in Pittsburgh who struggled with stuttering. Interviewee 6 was able to make significant progress with her stutter and she stated that even though she is no longer active with the NSA, she is a resource for women who struggle with stuttering. Other examples of giving back ranged from being a good friend to other people with disabilities to founding a disability non-profit and obtaining 501c3 status.
**Living beyond the stereotype.** Another unanimous theme that was drawn from the data was that interviewees were able to challenge low expectations and give back to the disability community by, as Interviewee 9 phrased it, “living beyond the stereotype.” Interviewee 10, who is currently enrolled in a Master’s program, reflected that she encounters people who tell her she “defied the odds” and she tells them that the challenges she experienced were due to barriers society placed in front of her, “that THEY placed in front of me!” Interviewee 10 explained further: “I defied them one at time, sometimes many at a time, and I didn’t let what society says or stereotypes become a part of my experience. They don’t have a place in my life.” The interviewees talked about their desires to live independently, have full-time jobs, attain higher education, and be influential figures in their communities in order to achieve standardized milestones of success both for individual gains and also to represent people with disabilities. But merely living beyond the stereotype wasn’t enough as the interviewees all claimed that it was their responsibility to make their achievements public in order to bring visibility to disability. Interviewee 2 elaborated that this responsibility, “to speak on behalf of an entire group of people, whether I want that burden or not” requires authenticity, integrity, humility, and equal partnerships with other individuals with disabilities.

**Bringing visibility to disability.** As unofficial ambassadors to disability and outspoken advocates, the interviewees all stressed that one of the best ways to improve how disability is perceived in society is to amend it with every day actions and accomplishments. All of the interviewees had Bachelor’s degrees, seven had either earned or were working towards a Master’s or doctoral degree, two interviewees held director level positions at their place of employment, two interviewees co-founded an
advocacy non-profit organization, and one interviewee has worked internationally on disability issues. By challenging prejudicial views and paternalistic standards through promotions, degrees, advocacy initiatives, and exemplary reputations, the interviewees were not only accomplished members of the disability community but impressive individuals according to mainstream societal benchmarks as well. Their hard work, their successes, and their action plans to achieve additional goals, all told through the interviewees’ authentic narratives, help reframe the social construct of disability by integrating it into every day life, thus making disability more accessible to an ableist society in dire need of social change.

The importance of narrative was made highly apparent during data analysis as the interviewees’ self-stories propelled them to act not only as individuals but also within their communities. As found by Mitchell and Snyder (2015), through narrative we not only shape our own lives but can better work together as neighbors, partners, coworkers, and professionals because it suggests possibilities for us all living together (as cited in Adams et al., 2015, p. 126). Each interviewee discussed their adherence to the social model of disability, which postulates that societal improvement requires individuals to address the flaws of an oppressive system and not cite inequities as the fault of the “disabled individual” (Adams et al., 2015). Thus it is a logical progression that the interviewees unanimously identified as advocates with a personal responsibility to improve how disability is experienced and in doing so amend the ableist narrative of disability.

In conclusion, as stated by Mitchell and Snyder (2015), “the understanding of narrative plays a crucial role in how we imagine social worlds” (as cited in Adams et al.,
2015, p. 126) and I argue, a crucial role in our ability to effectively improve these worlds as well. The materialization of a set of values and a sense of purpose, the development of meaningful goals that are aligned with this purpose, the construction of an identity that is both capable of creating an action plan and attaining these goals, and the individual’s perception that they are a self-efficacious agent—meaning they interpret their actions as causing desired change—results in the development of a change-agent who not only reaches individual goals but assumes responsibility for improving their community (Zeldin et al. 2014). All of the interviewees’ narratives reflected core principles of social cognitive theory and the youth-adult partnership model as evidenced by dialogue that included examples of their goals and roles, highlighted their sense of purpose, outlined their action plans, and elaborated on their responsibility as agentic leaders with positive disability-identities.

**Positive Disability-Identities**

My research initially sought to better understand the role disability-positive environments play in the development of agency amongst youth with disabilities in Pittsburgh. Instead, the interviewees chronicled how their perceptions of disability and identity evolved from their childhood experiences within the medical and charity model of disability up until much more positive experiences as self-determined young adults. While the interviewees’ answers did not directly touch on the concept of disability-positive environments, the key elements of disability-positive environments—generalizable skill building, advocacy opportunities, safe spaces, goal setting, problem solving, decision-making, and authentic learning opportunities—were seamlessly interlaced throughout the interviewees’ narratives. This study found that positive
disability-identities require agentic narratives that organize and describe established roles and goals as well as integrate a personally derived system of values. In turn this value system provides an overarching schematic structure that incorporates purpose, skills, accomplishments, and action plans with the basic objective of keeping interviewees’ identities aligned with their goals. Doing so increases the likelihood that the interviewees will successfully: navigate difficult physical and attitudinal barriers, tackle specific challenges in pursuit of their goals, craft a healthy sense of self, and be present in the disability community on their own terms.

The interviewees’ perceptions of their agentic identities matured over time and the benchmarks that signified that they were becoming successful young professionals centered on the interviewees’ roles as change makers, visible figures, relationship builders, and humble leaders who understood the importance of self-awareness, self-reflection, and their responsibility within their community. The aggregation of experiences, benchmarks, accomplishments, and authentic learning opportunities authored in the context of the interviewees’ social roles helped them process and make sense of feelings, beliefs, and perceptions about themselves. As found by Pennebaker and Seagal (1999), these stories serve as a means to “tie all of the changes in our life into a broad comprehensive story, stories that can be modified as additional events occur ensuring that these stories move the narrator forward and do not mire them in past experiences” (p. 1250). Ultimately the power of narrative provides a schematic framework enabling the narrator to practice self-awareness, self-reflection, and self-development, all desired objectives of social cognitive theory and the youth-adult partnership model.
In an ableist world that often short changes individuals with disabilities in their pursuit of a satisfying life, supporting youth with disabilities as they develop important skills and providing emotional scaffolding as they develop their self-perceptions can presumably make a significant difference in their quality of life. Interviewing ten young professionals about their experiences growing up with disabilities involved hearing their accounts of successes as well as stories chronicling negative experiences, moments of self-doubt, feeling socially isolated and excluded from facets of daily life, the struggle to form relationships, and encountering stigma and prejudice. The literature has shown that these factors all work to undermine the self-worth and resilience of individuals with disabilities that can lead to sub-par outcomes (U.S. Department of Education, 2014; U.S. Department of Health and Human Services, 1999; Sanford, Newman, Wagner, Cameto, Knokey, and Shaver, 2011; Scholl and Mooney, 2004; Barber, 2012; Erikson, Lee, and von Schrader, 2014; Newacheck, 1989; Babbit and Burbach, 1990; McCarthy, 1986; Enright, Conyers, and Szymanski, 1996; Field, Sarver, and Shaw, 2003; Kaplan, Salzer, and Brusilovskiy, 2012; Johnson, 1999; Bandura, 1989). The disability-positive environment model that I proposed as a method to counteract the damaging effects associated with disability oppression integrates key features of social cognitive theory and the youth-adult partnership model. However as I spoke with the interviewees about their development as autonomous, agentic leaders, the concept of the disability-positive environment had little relevance and traction.

After analyzing the interview data I was able to define five integrative themes: avoiding disabilities, epiphanic experiences, establishing goals and roles, agentic identity and disability-positive narratives, and positive disability-identities. These five integrative
themes revealed a pathway that all of the interviewees traversed. It documented the shared experience of denying disability due to internal and external stigma; the application of insight to redefine one’s identity, relationship with disability, and redirect their life trajectory towards positive pursuits; achieving self-determined goals; authoring a comprehensive narrative that propels the interviewee on their purposeful journey, ultimately resulting in their current identities and roles as successful young professionals. The integrative findings in this study are the organization and synthesis of this data into a model I call The Path of Advancement for Development of Positive Disability-Identities.

The Path of Advancement for Development of Positive Disability-Identities, which I will now refer to as The Path of Positive Disability-Identities, captures the five integrative themes the interviewees experienced during their transition from adolescence...
to young adulthood. The Path of Positive Disability-Identities maps out how during adolescence, interviewees actively avoided disability (Theme A), explores the epiphanic experiences that served as catalysts for orienting the interviewees’ sense of purpose and identity (Theme B), examines the roles adopted by each interviewee that furthered their ability to attain established goals and develop self-determination (Theme C), it situates the interviewee’s current agentic identity as it exists and is expressed by their disability-positive narrative (Theme D), and finally, the interviewees’ cumulative self-story, which consists of Themes A-D and is framed by the principles of disability-positivity, comprises the last integrative theme, the achievement of the positive disability-identity—or in other words, their identity as a successful young professional with a disability.
Chapter 5

Conclusions and Leadership Agenda

The Power of Narratives

The disability community is diverse and detailed, packed with a multitude of narratives that are insightful and meaningful commentaries on our primarily able-bodied, neurotypical world. As this study has explored, "disability" is an incredibly complex construct that was created and remains confined within the regimented dogma of a patriarchal, heteronormative, capitalist, racist, misogynistic, homophobic, xenophobic, Islamophobic, and ableist culture (Adams et al., 2015). The disability experience is systematically devalued, individuals living with disabilities are dismissed, and disability culture is denied. Our dominant cultural narrative of disability is authored disproportionately by individuals without disabilities who situate disability through the lens of the deficit model (Adams et al., 2015). Thus, how society understands disability is inauthentic, limiting, and discriminatory. The purpose of my work going forward is to confront this negative narrative of disability by empowering individuals with disabilities to lead their own lives, accomplish their own meaningful goals, and share their stories of overcoming society’s low expectations.

In this final chapter I will discuss the theoretical outcomes of my work, disability-positivity and the Path of Positive Disability-Identities, and the foundational theories driving this work, social cognitive theory and the youth-adult partnership model. I am mindful that my relationship with the larger disability community, my connection with self-advocates and disability-serving organizations, and my understanding of how disability is defined, perceived, and integrated is situated in the context of my
environment. My experience with disability is anchored in my practice in Pittsburgh, PA. To truly see the existing system and respectfully and responsibly improve the system requires the utilization of improvement inquiry. My partners in improvement consist of the interviewees as well as a network of leaders who share the common goal of engaging stakeholders, dismantling society’s ableist narrative, and hold the belief that change comes from the bottom-up through empowering individuals with disabilities. Authentic and comprehensive improvement hinges on incorporating insight and information from those directly impacted. Without meaningful engagement and honoring these voices, our ableist narrative will endure.

In addition to improvement inquiry, employing network leadership is crucial as it creates a shared language between advocates that enables the development of a cohesive agentic collective (Peurach, 2016). Ensuring that the members of this collective recognize a common cause, subscribe to the mission of the work, commit to forging effective, functional relationships between advocates and disability-serving organizations, and strive to coordinate improvement efforts is necessary in order to make positive change. The pursuit of social justice requires the intentional integration of diverse perspectives in conversations about change, educational efforts, and coordinated actions designed to improve how disability is perceived and experienced.

**Outcomes and Foundational Theories**

I found during each interview that the concept of disability-positive environments was not explicitly addressed by any of the interviewees despite there being direct questions in the questionnaire. The interviewees did not elaborate on past-participation in specific disability advocacy programs either but instead discussed the impact of
significant experiences, relationships, and realizations on their evolving perceptions of
disability, identity, and agency as youth and as young professionals. Specifically their
narratives referenced memorable and impactful experiences in which they acknowledged
disability, challenged how they thought about disability, and described the intentional
measures they took to change the trajectories of their lives. Ultimately the aggregation of
these factors resulted in the development of an agentic, positive disability-identity that
was guided by a cohesive sense of purpose and reinforced by establishing and achieving
meaningful goals.

**Principles of Disability-Positivity**

Despite the fact that disability-positive environments were not directly explored,
principles of disability-positivity played an integral part in each interviewee’s narrative.
While I had incorrectly hypothesized that the best way to nurture the development of a
disability-identity and the advancement of agency was through participation in a
disability-positive environment, I did find that essential elements of disability-positivity
surfaced in relation to unique experiences, recognized moments of conscientious
reflection, and through deliberate actions taken to reclaim identity and accomplish goals.

The paradigm of disability-positivity is founded on the social and biocultural
models of disability that argue that disability should not be perceived as a medical
diagnosis, a stereotyped status, or a lesser identity, but as a way life is experienced, which
can be significantly improved or damaged by cultural interpretations of ability and
difference. Through the lens of disability-positivity, disability is framed not as a limited
condition in and of itself, but as a condition that challenges our social, political, and
economic understanding of citizenry, productivity, human rights, and equity. In addition,
disability-positivity does not propose that disability is unequivocally a “positive” thing but rather disability is a diagnosis and potential identifier that is not unambiguously negative. Thus disability is not inherently positive or intrinsically negative, but personally nuanced, intimate, and complicated. Ultimately disability-positivity contends that there should be an equally distributed emphasis on both the embodiment of disability pride and individualized goal setting, agency, and action. In concert, this will shape a positive disability-identity and empower the individual to work towards attaining goals. To put it simply, disability-positivity claims that only individuals with disabilities have the right to define disability and to determine how disability factors into their identity.

Lastly, disability-positivity states that the stand-alone label of “disability” should not predict negative outcomes. Rather, access issues and systemic inequities surrounding disability should be recognized as products of a flawed ableist society and not the individual’s problem. Disability-positivity postulates that supporting individuals with disabilities as they come to their own conclusions about authenticity, autonomy, agency, and accomplishments is paramount in order to foster healthy disability narratives, amplify marginalized voices, and empower the disability community at large.

**Social Cognitive Theory and the Youth-Adult Partnership Model**

My framework, the Path of Positive Disability-Identities, is undergirded by Bandura’s (2001) social cognitive theory, which states that goals, self-efficacy, and conscientious reflection are necessary factors in the quest to lead a successful life. According to Bandura (2001), purpose, meaning, and the pursuit of life-satisfaction can be actively sought through establishing personalized goals and authoring a plan to attain them that is adaptable according to personal, cultural, and environmental changes. This
capacity for resilience was reiterated as an important skill by all of the interviewees in my study. The Path of Positive Disability-Identities framework also incorporates the prime components of the youth-adult partnership model—reflective learning communities, shared vision, and joint decision making—as the interviewees referenced these elements in relation to their maturation as empowered and active citizens. The essential elements of social cognitive theory, the youth-adult partnership model, and disability-positive environments were reflected in every narrative, not in the context of being a part of any disability oriented group, but highlighted in the interviewees’ accounts of their self-directed journey growing up in an ableist society. The interviewees’ narratives chronicled the advancement of their perceptions of identity, disability, and agency derived from seminal experiences that defined self-worth, impacted their definition of disability, showcased their effectiveness in problem-solving, and inspired action plans that pledged to advance how disability is understood and articulated in Pittsburgh via their own voices, actions, and visible legacies.

My Purpose, Values, and Practice

Disability Culture

In a world where being able-bodied and neurotypical is the desired norm, we are conditioned to believe that individuals with disabilities are inherently unfortunate, unhappy, and ever longing to be “normal.” We conclude that their lives are less-than because an individual with a disability lacks the capabilities of an able-bodied, neurotypical person. Their disability serves as justification to objectify the individual – they are their disability – and not in a way that incorporates disability pride, but rather as the reason to predict a life of limitations. Ableism faults the individual with a disability
for their inability to access every day life and in accordance with this rationale we often view accommodations as an inconvenience and not a matter of extending equitable opportunities (Adams et al., 2015; Campbell, 2015 as cited in Adams et al., 2015). The question, often asked subconsciously, presents itself: “Why should individuals with disabilities have the same level of access and the same rights as ‘normal’ people when they are innately different? Inherently less-than?” This macro objectification of disability results in denying individuals with disabilities equal rights on an individual, institutional, and systemic level. Integrating different bodies and minds in a structurally discriminatory system remains deprioritized. Change is slow and stagnant.

Mainstream society both objectifies and disempowers the disability experience. Our cycle of oppression consists of imposing paternalistic pity, the use of discrimination and stigma, our preoccupation with fixing disability, and refusal to acknowledge able-bodied, neurotypical privilege, all of which serve to reinforce our ableist framework (Adams et al., 2013). Individuals with disabilities are systematically silenced and relegated to the status of second-class citizens. In our ableist society we place more value on protecting the rights of able-bodied and neurotypical people, often at the expense of individuals with disabilities. Like with most marginalized groups, we sacrifice their rights in the pursuit of strengthening dominant culture.

One way we devalue individuals with disabilities is by robbing them of their self-defined identities and negating the existence of a distinct disability culture. The disability community has a rich history and a robust disability culture that involves language, shared beliefs, specific disability customs, expressions of pride, and widely recognized signifiers (Adams et al., 2015). Honoring disability culture and amplifying the counter
narrative to ableism—via empowering those with disabilities to tell their stories—is integral in the pursuit of social justice. This study afforded me the opportunity to explore disability culture through discussions with the interviewees about the unique aspects of their specific community and their personal relationship with disability pride and identity, and it gave me the chance to learn more about the respective and shared priorities in each community. Intersectionality, visibility and decision-making, and leadership and togetherness were all key areas in my conversations about disability culture.

**Intersectionality.** I am fortunate to have autistic friends who educate me about identity first language and autistic pride. I do not outright “belong” in the autistic world but as someone with a mental illness who is also neurodivergent, I'm able to bridge the divide with shared stories of struggling to fit in a neurotypical world. The camaraderie that comes with discrimination can unite a front. But even within a specific disability category there are distinct, individual experiences. Interviewee 3 is autistic and they spoke about how within disability categories there are varying degrees of in-group marginalization and similarly in most specific disability communities there is a hierarchy of visibility; i.e. *who represents autism?* Interviewee 3 explained that the “face of autism” has historically been a cis-gender white male with Asperger’s Disorder and their voices have overpowered the voices of other individuals within the autistic community. The experiences and needs of cis-gender white males with Asperger’s Disorder are prioritized above all else. As Interviewee 3 explained, they are viewed as “actually autistic” and this has led to a sense of entitlement and privilege that disenfranchises other autistics.
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The monopolization of representation touches every disability category and it fundamentally serves to de-prioritize the experiences of minorities within the category, especially when it comes to intersectionality. Until recently intersectionality in disability culture has failed to gain much attention both across the larger disability community and within specific disability groups. This lack of in-group recognition has caused significant problems as different sub-groups have different needs, concerns, and advocacy goals. Intersectionality in the disability community is a hot button issue as it challenges the status quo, shifting power from those who historically had decision-making authority to other members of the group who previously were voiceless or muffled. As Interviewee 3 explained, we live not only in an ableist world, but within specific disability communities there are also hierarchies that must be challenged and leveled.

**Visibility and decision-making.** When it comes to discussing hierarchies there are ongoing arguments across the disability continuum, most of which are centered on the experiences and challenges that come with invisible versus visible disabilities. Interviewee 2, a person of color with an invisible disability, discussed how in Pittsburgh the expected “disability spokesperson” is an affluent, older white person who has a visible disability. He added that these are the faces you see serving on disability task forces organized by Allegheny County, these are the individuals invited to join boards who stay seated for years, and overall he explained that it reveals a reluctance to change up the decision-makers in Pittsburgh’s disability advocacy community. Interviewee 2 posed the question, “why is there no transfer of power to new advocates with different disabilities, different races, and new perspectives?”
But bringing visibility to disability was also described as a top priority for the interviewees who use wheel chairs. Interviewees 7 and 9 work down town and they both articulated that there are only five or so people total who use wheel chairs, work in a professional capacity, and navigate down town Pittsburgh with the attitude of “we belong here, too.” They also each mentioned with a chuckle that all of these individuals use the same parking garage. Interviewees 7 and 9 stated that able-bodied people do not see enough wheel chair users integrated into every day life and this segregation solidifies misconceptions about disability, ability, and the right to equitable space. Interviewees 7 and 9 both explained how visibility is important in order to stake claim in an able-bodied world. In turn Interviewee 2 maintained that the visibility of invisible disabilities is paramount in order to ensure equitable decision-making power in formal advocacy channels in Pittsburgh. The interviewees all argued for the right to space, opportunity, and power—attainable goals guided by a strong sense of purpose. Partnership between the visible and invisible disability community is primed but intentional linkage is still needed.

**Leadership and togetherness.** Each specific disability community has its own nuances, customs, language, associations, and identities. Conversely, each specific disability community also has its own stereotypes, prejudice, attitudinal barriers, and stigma that it encounters and must challenge on a daily basis. Though there are a multitude of disability categories—which at times have been isolated and segregated from one another—in Pittsburgh, as reported by the interviewees, the disability community strives to embrace and amplify the entire community’s strengths, values, and goals, albeit with varying degrees of success. Pittsburgh’s disability community is united
under the sentiment “nothing about us without us” and the community intentionally labors to create an advocacy body that respects and raises up diverse narratives. However, as I learned from the interviewees, there is a definite need to both fill existing leadership roles and carve out new influential positions for young professionals with disabilities. Interviewees 2, 4, 7, and 10 outlined that there are qualified disability advocates who still serve token roles rather than being transitioned to more meaningful positions. To paraphrase Interviewee 7, these individuals can do more than contribute to disability issues, they can spear head the problem solving. This affirms my own perception that youth with disabilities are inadequately incorporated into existing formal advocacy structures in Pittsburgh.

Despite the predictable and unpredictable challenges experienced within specific disability categories and the larger disability community, all of the interviewees were thankful to have a place to belong. The interviewees explained that in a world where disability is viewed as limiting and lack of access is widespread, finding other people who have experienced the same struggles is validating, empowering, and the first step in mobilizing advocates. As in any minority group, relationships serve a meaningful and powerful purpose. During my interview with Interviewee 3 I asked them what the disability community had done for them. They answered with the following:

[The disability community] enabled me in a way that the abled community disabled me. It taught me that I can practice self-determination and agency without having to ‘overcome.’ I can live ‘being different’ without being less. I mean—I can be disabled and not be less—and I am.
To explore this even further, Interviewee 6, who has a stutter, explained that people with disabilities have the power to take control of their own lives but they also have an obligation to bring authentic positive changes to the disability community. Interviewee 6 likened this charge to that of any minority group, saying:

Ultimately, you have to create your own story. Write your own story and empower yourself. Anyone living a minority experience, whether it is race, disability, gender identity, etc., these stories need to be articulated, documented, and shared to make a difference in how dominant culture defines “difference.” Your story is one of many and that can make an impact.

Like all of the interviewees, Interviewee 6 outlined the responsibility of successful advocates to continue challenging disability oppression through their own accomplishments, efforts, and by supporting others within the disability community. Togetherness was expressed as vital for progress, to offset advocate burnout, and in order to sustain change. Recognizing all disabilities, championing intersectionality, recruiting diverse advocates to apply for leadership positions, critically reflecting on how authority and decision-making power is passed to individuals, and making concerted efforts to bring people of color, members of the transgender community, and individuals living in poverty into disability conversations is pivotal in order to authentically reflect the disability community. New advocates, new experiences, new narratives, and new ways of thinking about disability, identity, and agency need to be welcomed or the disability community’s advocacy efforts will become stagnant. A stunted status quo would only serve to perpetuate the cycle of inauthentic disability narratives and oppression.
Leadership Agenda

In the United States, intentional ignorance, the use of stigma and discriminatory practices, disrespect and disempowerment, and systemic abuse culminate in the widespread practice of ableism (Adams et al., 2015). Through my personal experiences living with a disability and my practice in the disability community, I’ve witnessed the impact of our dueling narratives of disability: ableism vs. the voices of individuals with disabilities, which I’ve explored in my dissertation as examples of disability-positivity. I believe that individuals with disabilities who have redefined disability and ability, cultivated their own sense of identity, and can effectively practice agency can challenge generalized low expectations predicated by ableism by accomplishing their own genuine achievements. Ableism can be replaced by agency.

This study afforded me the opportunity to interview friends and colleagues who are impressive forces in Pittsburgh’s disability community. These individuals are all objectively successful; they have careers, degrees, and have been recognized as leaders and advocates across the state of Pennsylvania. During their interviews they all reported feeling happy and fulfilled with their personal lives while remaining cognizant of the detrimental effects that come with living in an ableist culture. Each interviewee expressed how staying true to their own identities as advocates necessitated becoming leaders in the disability community and being visible change makers in our able-bodied, neurotypical world. Adopting and acting on their leadership role aligned their values, sense of purpose, skills, accomplishments, and informed their action plans as individuals who all stated that giving back and making a difference was integral to their own existence. Ultimately this study emphatically confirms—albeit on a small scale—that we need to challenge our
ableist, deficit-dominated definition of “disability” with empowered positive action both by developing leaders with disabilities and by engaging those who subscribe to ableist ideologies.

**The ADA Generation**

The legal landscape of disability rights in the United States has improved significantly since the 1970s. The tireless work of parents and self-advocates has resulted in the adoption of legislation designed to increase individual, institutional, and systemic access as well as protect the rights of individuals with disabilities on a federal level (Wang, Mannan, Poston, Turnbull, and Summers, 2004). The enactment of Section 504 of the Rehabilitation Act of 1973; the Education of Handicapped Children Act of 1975, which was amended in 1990 and renamed the Individuals with Disabilities Education Act (IDEA), which was in turn further amended in 1997 and 2004; and the Americans with Disabilities Act (ADA) of 1990 signified a shifting cultural ideology that began to frame disability rights as civil rights. In particular the ADA has been viewed as a fundamentally important piece of legislation as it outlines that an institution cannot have practices that will screen out individuals with disabilities and they must make reasonable accommodations, modifications, and provide equal opportunity, not just equal treatment, for all individuals in an integrated setting (Nott and Zaffè, 2006). Under the auspices of this new legislation, “disability” went from being a justification for segregation to being a protected class. The children, adolescents, and young adults coming of age during the enactment of the ADA were the first generation of individuals with disabilities being invested in as full citizens under the law.
The interviewees in my study are all members of the first generation of young people who came of age under these laws. Referred to as the ADA Generation (the Institute for Educational Leadership, 2014), they grew up in a society where the government pledged to protect and support their right to a free and appropriate public education and prohibit discrimination in all areas of public life, including education, transportation, and employment (Adams et al., 2015; Nott and Zafft, 2006). But, even though disability was now a part of a national conversation, change takes time. The interviewees spoke of pivotal legislation like the ADA but they also discussed the prevalence of physical and attitudinal barriers they encountered growing up with a disability. However, for the interviewees and their family members, there were now formal channels through which protections were granted and where complaints could be filed when services were inadequate or not fulfilled (Wang et al., 2004; Sabatello, 2015 as cited in Adams et al., 2015). Barriers existed but now there was a means to address discrimination and theoretically achieve equitable access.

The United States’s relationship with disability, equity, and inclusion—especially in regards to the public school system—has been rife with discriminatory policies and overall boasts a history of denying students with disabilities access to an education (Price, 2015 as cited in Adams et al., 2015; Sabatello, 2015 as cited in Adams et al., 2015; Wang et al., 2004). An example of the systematic oppression of disability in our society is the fact that parents have to fight to ensure services and opportunities for their children without much legal recourse supporting them (Wang et al., 2004). Since the 1970s, policy makers and school administrators’ expectations have been clear: parents are to serve as the watchdogs for their children’s right to a fair education (Wang et al., 2004). The IDEA
of 1990 was explicitly designed to protect the rights of students with disabilities by ensuring that every child receives a free and appropriate public education regardless of ability (Nott and Zafft, 2006). However, even with the passing and implementation of this legislation, parents and guardians are still expected to serve as the “accountability mechanism” to ensure that IDEA mandates are enforced (Wang et al., 2004) similar to how the ADA is a complaint-driven mandate. This expectation set the precedent that it is the responsibility of guardians to fight for their children’s rights and that they have to serve as the “police” of the public school system to make sure accommodations are appropriately implemented. Guardians are tasked with the responsibility of being advocates, which often means fighting with the school for their child’s rights. For these families, advocacy has become adversarial due to lack of state and federal responsibility (Wang et al., 2004).

As mentioned earlier, for both the IDEA and the ADA, those benefitting from the law have the burden of ensuring it is upheld by filing complaints and grievances. It is safe to assume that the nature of this legislation has influenced the development of the parent-advocate and the self-advocate in regard to roles, responsibilities, and a sense of identity. The interviewees in my study all shared narratives that were written through the schematic framework of positive disability-identities. Their self-stories detailed their development as self-advocates and agents, included stories about challenging attitudinal and physical barriers, outlined their epiphanic experiences and their impact on shaping identity and purpose, and examined how the interviewees learned to establish and achieve self-determined goals. The interviewees, members of the ADA Generation, grew up in an environment where resources existed but accessing them was not a guarantee—a reality
that the interviewees were astutely aware of. This legal and cultural climate produced young people who knew that access was hinged on their ability to become effective advocates, which involved understanding their rights under the law. In alignment with this advocacy trajectory, it makes sense that the interviewees have developed as educated self-advocates who effectively navigate and narrate their own stories. The ADA Generation is authoring a new story in which disability is no longer voiced by parents, but by self-advocates. Their perspective as young people living with disability is shaped by their experiences living under the law and the label, their efforts to reclaim and cultivate identity, their contributions to disability culture, and through challenging society’s low expectations as a counter narrative to the language of an ableist culture.

While there is significantly more work to be done in regard to ensuring disability rights, especially in regard to individual, institutional, and systemic accessibility, young people with disabilities—the ADA Generation—are at the forefront of the fight. The solidification, popularization, and dissemination of disability culture have resulted in increased solidarity and the amplification of diverse, intersectional disability narratives. By creating space for voices that challenge low expectations, we are seeing new opportunities forged by young advocates who subscribe to a culture of self-determination. This narrative often uses identity first language, it is rich with expressions of disability pride, and it is aligned with a disability movement that rallies around action, integration, equity, and opportunity. My research just begins to explore how this generation of young people—the first wave of individuals impacted by federal legislation, the first wave of youth growing up with recognized disabilities and recognized rights—has developed as advocates and leaders. I believe that the interviewees’ narratives have informed the
development of the concept of positive disability-identities and led to the intentional creation of a disability culture. The narratives reviewed in this study include examples of legislative literacy regarding disability issues, involve appreciation of the work of advocates in the past and investment in disability history, and express the need for the interviewees to make things better for the disability community by living beyond the stereotype. The ADA Generation has its own story to tell and I hope to explore the messages, lessons, and practice of leadership in future research.

**Improvement Inquiry and Network Leadership**

My leadership agenda is driven by improvement inquiry and network leadership with the end goal of challenging and re-writing our ableist narrative of disability. Network leadership is an educational strategy that aims to effectively harness the energy, skills, and resources of invested leaders who share a purpose and a common approach to improvement (Peurach, 2016). Following the completion of this doctoral program I plan to adopt the network leadership model in order to start the development of a cross-disability advocacy collective comprised of young professionals with disabilities. In accordance with network leadership, this collective will be designed to coordinate improvement efforts, and provide advocates and leaders with resources. It will serve as a platform to build relationships, as a forum that facilitates the sharing of ideas, and overall it will strengthen partnerships between stakeholders.

The practice of network leadership demands continuous collaborative learning in order to function effectively (Peurach, 2016). With this in mind an integral element of this advocacy collective will be education. In Pittsburgh while there are cross-disability initiatives, there is minimal cross-disability education. This became apparent throughout
the interviews as the interviewees discussed the cropping up of advocacy silos and a
struggle to authentically and respectfully integrate. This was influenced partly by a lack
of information about specific disabilities as well as not knowing the specific needs of
those communities both locally and nationally. For example, Interviewee 7 explained that
had he not gone to a national cross-disability conference he would have never realized
that wheelchair users and individuals with invisible disabilities share a strong history,
share similar struggles in our inaccessible world, and he would have never witnessed the
power of the comprehensive disability community.

Based on the conversations I had with the interviewees, my first step in the
development of an advocacy collective is to create a space for peer-to-peer education.
Interviewees 2, 3, and 4 spoke of the effectiveness of the peer model by name and the
remaining interviewees emphasized the importance of increasing understanding about
disability through educational efforts, friendships, and helping others. In this collective,
leaders will be able to teach each other about different disability communities, the
respective needs of each community, how distinct disabilities are impacted by ableism,
their perceived status in Pittsburgh’s disability advocacy efforts, the criticality of
intersectionality, outline current advocacy initiatives for each disability community, and
expand upon opportunities for partnership. Ideally this collective will support and
empower advocates across the disability continuum to make changes within their own
communities, work together in targeted ways, as well as serve as a platform to
intentionally amplify strong, new disability narratives.

To quote Interviewee 10, “the more we advocate, the more the world opens up.”
Or in other words, as we rewrite society’s ableist disability narrative, we begin to exist as
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a recognized culture entitled to equal rights and equitable access to societal systems that promote successful outcomes. As discussed throughout my dissertation, our current damaging, inauthentic disability narrative needs to be rewritten by leaders with disabilities. Valuing the disability experience is a critical first step in order to nurture disabled voices, improve outcomes, and celebrate disability culture. Change is a matter of social justice. It is evident that progress will only be a product of collaboration, communication, education, and a dedicated advocacy collective committed to challenging ableism.

Limitations

This study sought to answer two research questions. The primary research question was: How and to what extent do youth with disabilities perceive disability advocacy programs in Pittsburgh as disability-positive environments? And the supplemental research question was: How do young professionals with disabilities perceive and describe living with a disability, developing an identity, and maturing as an agent in the context of past participation in a disability advocacy program? This study collected qualitative data through semi-structured, in-person interviews. Data were organized and analyzed using Template Analysis, contextualized through the parameters of social cognitive theory, the youth-adult partnership model, and principles of disability-positive environments. Due to both financial and time constraints, non-probability sampling methods were employed in order to recruit participants. I used a voluntary sample as well as a convenience sample to recruit ten interviewees who were included in the study.
Recruiting interviewees who fulfilled the qualifying criteria—young professionals with disabilities who had past involvement with a disability advocacy program as youth and currently identify as advocates today—proved challenging as the study had to meet certain deadlines. Time constraints contributed to the lack of diversity in the study overall as I had to rely solely on a somewhat limited professional and personal network. Recruiting a more diverse group of interviewees might have yielded a broader set of findings. Moving forward, recruiting and including interviewees who represent the full spectrum of disability, have different ethnic and racial identities, and are members of the queer community would potentially offer a much more authentic and intersectional perspective and methodological approach to conducting this research. The involvement of more interviewees would have also provided a larger sample size, afforded the opportunity to scale the study, and increased the potential for generalizable findings. A convenient pool was the only population utilized in this study, thus the data only provides a springboard to examine the ideas suggested in the work, and no other conclusions can accurately be claimed.

The interviewees in my study can all be classified as members of the ADA Generation (the Institute for Educational Leadership, 2014); a term coined for the first generation of young people who came of age under the Americans with Disabilities Act as well as other landmark legislation that was designed to prevent discrimination against those with disabilities. As mentioned previously, historically, families raising a child with a disability have struggled for inclusion and they continue to struggle in the pursuit of securing equitable access in education and protecting their children’s rights on an institutional and societal level. Parents and guardians have always served as a powerful
bloc of advocates who have fought both in their local school districts and on a national level for the enactment of legislation that integrates individuals with disabilities into everyday life (Wang, et al., 2004). Members of the ADA Generation were raised as self-advocates and I postulate that the momentum of their guardians’ actions in conjunction with their own relationship with disability and identity has resulted in an unprecedented movement towards increased access, equity, autonomy, and agency. The emergence of the ADA Generation and their potential impact on confronting ableism, authoring a new disability narrative, contributing to an already expanding disability culture, and impacting how disability is researched, should be explored further.

Unfortunately, my interest in better understanding the role of family came too late in the development of my study. While each interviewee spoke of their involvement with family members I did not document the frequency or nature of contact with family members, details regarding their relationships, the level of importance assigned to specific relationships, nor did I quantify the number of positive or negative interactions between significant family members. Family members were mentioned in the interviews but my follow-up questions regarding the overall influence of family were limited. My primary focus on assessing the interviewee as an agentic self-advocate and examining the role disability-positive environments played in their lives narrowed the lens through which I viewed the study. Unwittingly I treated family members, particularly parents and guardians, as cursory details. This shortcoming significantly and undoubtedly impacted the outcomes of my study. Moving forward, recruiting diverse interviewees, having a larger sample overall, and including research questions that address the role of the family—particularly guardians—are of notable interest as this expansion could result in
more broadly applicable findings. I believe that exploring the role of family in the development of agency for the ADA Generation will yield meaningful results as I contend that family systems provide valuable context in the formation of a disability-identity. I am eager to continue this work.

**Exploring My Positive Disability-Identity**

Epiphanic experiences, a product of my research, create space for introspection, opportunities to renew self-image, and they afford individuals with disabilities the chance to scrutinize how society understands and treats disability. Epiphanic experiences also serve as a call to action—the tipping point that informs an individual’s next steps—creating tangible plans as they move towards adulthood and develop as agentic leaders. I’ve determined that epiphanic experiences ultimately ask the following questions: “Who am I?” and “What do I want to do?” From my first day as a doctoral student this journey has been a meaningful epiphanic experience as it has continuously encouraged my own critical reflection and action. Thus I find it appropriate to conclude my dissertation by answering the same questions I posed to the interviewees.

*Who am I?* I am a practitioner and a scholar. Through reading the literature and conducting research I have gained perspective in regard to understanding problems, asking the right questions, and making systematic improvements in my community. I situate myself in this work not only as an educator and a self-advocate with bipolar disorder, but also as a community organizer in Pittsburgh, PA. *What do I want to do?* I want to maximize opportunities to forge cross-disability partnerships by continuing my work with advocates and disability-serving organizations. I personally want to challenge low expectations predicated by ableism, give back to my community, live beyond the
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stereotype, and bring visibility to disability by reclaiming and re-writing ableist disability narratives to authentically reflect intersectionality and the changing face of disability in Pittsburgh. I’m ready to tell my own story, I’m committed to take positive action, and most importantly I promise to keep listening to my partners in this work.
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Appendix A

Perceptions of Disability Instrument

Study Background
Primary research question: How and to what extent do youth with disabilities perceive disability advocacy programs in Pittsburgh as disability-positive environments?

Supplemental research question: How do young professionals with disabilities perceive and describe living with a disability, developing an identity, and maturing as an agent in the context of past participation in a disability advocacy program?

Disability-positive environments are programs that foster skill building, provide advocacy opportunities, and support youth with disabilities as they explore their self-efficacy and establish goals within a safe, culturally competent, and inclusive framework. These environments maintain high expectations and promote authentic learning for youth with disabilities who are viewed as autonomous, agentic leaders.

Questionnaire

Disability, Identity, and Agency

As a young adult:

1) How did you define disability?
   a. Provide an example of how this was expressed in your life.

2) How did you define your identity?
   a. Provide an example of how this was expressed in your life.

3) How did you define agency?
   a. Provide an example of how this was expressed in your life.

As an adult:

1) How do you define disability now?
   a. Provide an example of how this is expressed in your life.
2) How do you define your identity now?
   a. Provide an example of how this is expressed in your life.

3) How do you define agency now?
   a. Provide an example of how this is expressed in your life.

Experience with Disability Advocacy Programs

(1) Please circle the focus areas of the disability advocacy program you participated in as a young advocate (please circle all applicable options):

   - Leadership
   - Accessible athletics
   - Education
   - Health care
   - Vocational training
   - Peer support
   - Social skill development
   - Other. Please explain.

(2) Why did you join this disability advocacy program?

(3) When you were a young adult, how did you feel about participating in this program?

(4) As an adult, how do you feel about your experiences with the program?
Exploring Goals
(1) Did the program emphasize the importance of goal setting?
(2) If so, did you learn strategies that helped you set and attain goals as a young adult? Can you provide an example?
(3) How has your competence and confidence level when it comes to setting, planning, and going after personal and professional goals been influenced by your experiences in a disability advocacy group or in the disability community?

Program Assessment
(1) What was your favorite aspect of the program and why?
(2) What is a key takeaway from your experiences with the program?
(3) What is at least one thing you would do to improve that program?

Present Relationship with the Disability Community
What is your involvement with the disability community today? Indicate all that apply.

1) Professional - Primary
   a. Work directly with individuals with disabilities
   b. The field directly addresses and impacts disability. Examples: academia, policy, government, access, etc.

2) Professional – Secondary
   a. Work in a field in which disability competencies play a part but are not integral elements of your position or work responsibilities

3) Volunteering
   a. Supporting any aspect of disability in any domain as a non-paid volunteer.
      Examples: accessible sports teams, fundraising efforts for non-profits or charities, working with young people with disabilities as a formal or informal mentor, etc.
4) Serve on committees, task forces, or advisory boards as a representative of the disability community

5) Peer support
   a. Work or volunteer to support peers with disabilities in a variety of life domains

6) Nothing other than living with my disability

7) Other. Please explain.