

Forming a Positive Disability Identity through Participation in Youth Arts

Programs

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To make art is to reflect outward. Youth art has great potential to function as an opportunity to self-heal and express openly without hesitation. The benefits of youth arts programs in the United States have been a long discovery of best practices, evaluation methods and striving for state and federal support. It is clear that all children, regardless of economic or social circumstances or the range of abilities or disabilities they have, benefit from strong community support as they make their way into adolescence and adulthood. Such support is often found in a caring family, a school that values a range of opportunities and educational environments for children, a community that values safety, creativity, and a culture that promotes the building of healthy relationships and respect for all people. According to Goss (2007), a researcher in the Culture and Youth Arts Development Initiative, “It has been demonstrated that culture and arts programming is important in the healthy development of young people,” (p. 8). While there is a plethora of research that illustrates the importance of arts programs in fostering positive youth development, this paper will address the positive role of arts programs outside of schools and community centers which target disabled youth. Through an unpacking of the term “disability” and brief case studies of each the Partners for Youth with Disabilities (PYD) organization, The Miracle Theatre Project and the VSA Arts Volkswagen youth arts competition, this paper will illustrate the essential role of theatre and visual arts for disabled youth in developing and sustaining a positive disability identity.

In this paper, the term “disabled” will be used to describe youth that face daily physical or mental challenges. After substantial research, it is the most appropriate term to use in an arts context. Still, it is reasonable that the term be unpacked before beginning

to explain youth disability arts programming. The term “disabled” is grounded in controversy and history. According to the Merriam Webster Online Dictionary (2013), “disability” has two definitions; “1: A condition such as illness or an injury that damages or limits a person’s physical or mental abilities” and “2: The condition of being unable to do things in the normal way.” The same dictionary defines “ability” as “the power or skill to do something.” The definition given by the Merriam Webster Online Dictionary for the term disability is incomplete and should be redefined. Many disabilities, especially developmental disabilities and learning disabilities, are rooted neither in illness nor injury, but rather abnormalities occurring randomly in pregnancy and other uncontrollable environmental pressures. Illness and injury are negative and limiting terms, and can in effect further marginalize people with disabilities.

According to Barnes and Mercer in “Disability Culture” (2001), in the early 1980s, Americans were becoming increasingly sensitive to groups of people who were marginalized due to terminology and institutional structure (p. 517). This time period saw the rise of feminism, movements which would define and defend the social rights of women. The early 1980s were still in the aftermath of the civil rights movement, including social transformations focused on establishing equal political, economical and social rights for all people. According to the Oxford Online Dictionary (2013), because of these social upheavals and others, in the early 1980s the term “disabled” was in some areas of the United States replaced by the term “differently-abled” to describe those individuals who were for whatever reason perceived as abnormal in an effort to focus on the abilities of an individual rather than the disabilities. The Merriam Webster Online Dictionary lacks a definition of “differently-abled”, suggesting it is merely an adjective

of “disabled.” It has no doubt been difficult throughout history to place a label on those individuals who face daily challenges, as most every person faces some physical or psychological challenge in a lifetime. According to Tapia and Kaufman in “Diversity Best Practices Journal” (2011), 50 million people in the United States and 1.1 billion people worldwide have some type of physical or cognitive disability. According to Haller, Dorries and Rahn in “Disability and Society” (2006), in the last 15 years, the passage of the Americans with Disabilities Act (ADA) and advocating by the US Disability Rights Movement, there has been even further transformation of the term “disabled” (p. 62). Haller et al. notes that recently, using “differently abled” as a term is less socially accepted, although still often “politically correct” as the term suggests that a person does not have more abilities, but rather lacks certain essential or expected abilities (p. 67). It suggests perhaps, that some imbalance remains, and for that reason, does not accomplish the goal of providing a more inclusive, non-stereotypical term. No matter the terminology that has been cycled through the American cultural language in the past half-century, the World Report on Disability (2011) found that “people with disabilities experience lower educational achievements, fewer economic opportunities, poorer health and higher rates of poverty than people without disabilities.” The report, quoted by Tapia and Kaufman, urges governments to “step up efforts to enable access to mainstream services and to invest in specialized programs to unlock the vast potential of people with disabilities” (para. 10). While government programs have funded many organizations aiding in the personal welfare of persons with disabilities, in this paper, I will discuss some of the specialized programs and services that have been established by communities to aid in the development of a positive identity in youth with disabilities.

According to Sulewski, Boeltzig and Hasnain (2012) in “Disability Studied Quarterly,” before 1980, disability was often times viewed as being rooted in the individual, rather than socially created (para. 3). The more contemporary notion that disabilities are at least partially social constructions is empowering for those living with disabilities. Sulewski states that this notion “recognizes that (disability) is not a biological or natural property but an elastic social category subject to social control and capable of effecting social change (para 3). That is to say, if something can change according to outside influences, it can also be influenced by the personal will of the individual. Sulewski et al. explains the “disability culture” that emerged from this notion, defined by groups of people who believed they should no longer be ashamed of their disabilities and had every right to define their own identities. The arts have played a significant role in the progression of disability culture and inform the arts programming structure of several youth disability arts organizations. Young artists, states Sulewski et al., could make artwork “not in spite of their disability, not because of it, but including it” (para 5-7). The arts have played a strong role in the progression of this disability culture. Arts instruction plays a strong role in building the self-esteem of youth on an individual level, including those with disabilities (para 10). A positive youth disability identity is built on opportunities for empowerment, especially those that promote self-confidence and social interaction. In “Disability and Society” (2005) Taylor found that arts education helps disabled youth “engage in a process of self-realization in which they “identified and addressed negative and oppressive perceptions of disability through their artwork” (p. 763) As a result, suggests Taylor, the youth were able to adopt a more positive, inclusive and multi-identity perspective (p. 763). In the recent decade, youth disability arts have

transformed from a way to “fix” one or more parts of a “troubled” child to helping youth with disabilities find ways to turn what challenges they face into opportunities for self-discovery. Self-discovery is one category within the development of a positive identity, as is personal empowerment. According to Catalano, Berglund, Lonczac, Ryan and Hopkins (2002) in “Positive Youth Development in the United States,” empowerment is found within many processes, such as exercising leadership, helping in the community, building skills, taking risks, interacting socially, building friendships, and more (p. 100).

One organization striving to advance art opportunities for young people with disabilities is the VSA Arts and Volkswagen of America project, which “develops programs to increase access to the arts and educational inclusion with and for youth with disabilities,” as stated by Sulewski et al. (para 10). VSA Arts, the International Organization on Arts and Disability, provides teachers, parents and artists with resources to support arts programming in communities (para 19). VSA arts partnered with Volkswagen of America in 2002 to create the VSA arts/Volkswagen competition for young artists with disabilities. The goal of the program is to boost the participant’s young professional development in the hope that more youth with disabilities might be encouraged to enter art professions as adults (para 20). One purpose of the project is to bring awareness to the underrepresentation of artists with disabilities in museums and arts programs nation wide. Applicants, who are largely high-school aged youth, may enter up to five pieces of artwork in an annual VSA competition, created in response to a given theme. According to the Kennedy Center website page “VSA/Volkswagen Group of America Exhibition Program”, The 2011 theme was “Momentum,” urging artists to explore the “creative spark behind their work, the force that drives artistic interest,” the

2012 theme was “Sustaining/Creating” and the 2013 theme was “Infinite Earth”, asking young artists for “innovative viewpoints at the intersection of environmentalism, creativity and disability.” (Kennedy center 2013). Winning artists are chosen by a panel of jurors and awarded cash awards between \$2,000 and \$20,000. According to Sulewski et al. (2012), youth work is also included in an art exhibit at the Smithsonian Institution in Washington D.C. (para 28). Such a national arts competition calls upon youth to examine their position as young people nearing adulthood, artists in training, and people with disabilities. To help youth understand these sometimes difficult to reconcile identities, the arts competition serves an important purpose as a positive outlet and a chance to win not just money, but hope, which is one of the goals of the VSA Arts programming (para 22).

Included in all youth arts programs should be a governing set of most valuable teaching practices and program goals. Outlined by Catalano et al. (2002), youth arts programs should strive to achieve one or more of the following objectives: “promotes bonding, fosters resilience, promotes social, emotional, cognitive, and behavioral competence, fosters self-determination and efficacy, fosters a clear and positive identity, and provides opportunities for social involvement” (pp 101-102). Sulewski et al. (2012) offers a very similar set of program goals for youth with disabilities, noting the most important as “self-acceptance, building strong friend and family relationships, using art as a way of communicating visually about one’s disability and inner identity dilemmas, and using art as a way of coping with negative aspects of disability, anxiety and depression” (para 54).

Sulewski et al. researched the role of VSA arts in the individual lives of several

young artists. A number of the participants voiced that “making art helped them cope with stigmas, fear, and pain associated with their disabilities” (para 42). One artist wrote in an artist statement about his piece that it became “a road trip through my past. Going through my past helps to figure out who I have become” (para 42). Some artists, as researched by Sulewski et al. (2012), found that making artwork helped them more easily communicate with others about their disability. One such participant noted that making artwork for the VSA competition helped him shift his identity perception from a person with disabilities to a young artist (para 43). In the years following the VSA Arts competitions some winning artists did choose to pursue art as a career, as the flexibility and transformative nature of art can prove quite accommodating to those with a range of abilities and disabilities (para 45). Through participation in the VSA Arts competition, youth gain self-determination, a fostered resilience to outside pressures, and a clearer, more positive disability identity.

As expressed by many arts professionals, providing ample opportunities for social involvement is an essential component of youth arts programming, especially for youth with disabilities. The Miracle Project, founded in 2004, helps children and teens with autism and other special needs to express themselves through music, dance, acting, story and writing (Hall 2013). It is based out of NYC, New York and operates in Los Angeles, and recently in Ethiopia. As autism is often thought to hinder a child’s ability to socialize, the focus in The Miracle Project is on socialization opportunities and community building to cultivate an accepting and growing positive environment. While the process of learning lines to act out in a play or memorizing a song to perform calls forth a great deal of memory and skill, the youth participants are also able to gain self-confidence through

taking part in plays and expressing themselves in large groups (Hall 2013). A tagline on The Miracle Project website states, “socialization, communication and sensory processes” as class goals (Hall 2013). The founder of the Miracle Project, Elaine Hall, originally experienced the power of theatre and interactive arts in helping build positive self-development in young people when her son was diagnosed with severe autism and wasn’t responding to traditional therapies. In a 2011 interview with CBS news correspondent Pat Harvey, Hall notes that when her son was flapping his arms one day, she began to flap hers. “We were birds together. Rather than pulling him into my world, I was able to pull him into mine” (Hall 2013). This sense of mutual understanding through play, call and response, active participation and above all, respect, became a platform for theatre arts programming within The Miracle Project. Autism is sometimes thought of as an invisible disability, and is often feared because it is not well understood. This is not so different from many other developmental disabilities. The Miracle Project’s specific programming shows the public that contrary to common assumptions, autistic children are not by nature lacking in certain socialization abilities and each child, autistic or not, has certain abilities which are more prominent than others. Hall stated in her interview, “every child, autistic or not, has special needs.” Seeking those needs out, especially early on, is profoundly empowering for positive youth development. When interviewed by Harvey, one Miracle Project participant stated of his experience, “it’s taught me to be accepting of the word autism because I used to not be accepting. Autism is something to be proud of.” Another stated, “I can beat the (autism) spectrum. I can beat who I am” (Hall 2013). According to Catalano et al. (2002), opportunities for empowerment are found in leadership roles, community togetherness, skill building, risk taking, social

interactions and friendship building. As a positive self-identity is rooted in opportunities for personal empowerment, the Miracle Project does well in expecting participants to take part in all areas of theatre production. This includes rehearsing lines, attending classes, inviting friends and family to large-scale productions and learning to accept one another and themselves for the strengths and weaknesses they each have.

A third organization which utilizes the best practice techniques outlined by Catalano et al. (2002) and program goals suggested by Sulewski et al. (2012) is the Partners for Youth with Disabilities project based out of Boston, Massachusetts. According to the Partners for Youth with Disabilities informational website (2013), since 2003, it has grown from one arts program to five well developed programs serving hundreds of youth with disabilities, “promoting inclusive practices, self-esteem, healthy lifestyles, career development for youth and young adults ages 6-24 who face daily challenges” (para. 1). One of the main programs is called Access to Theatre. Access to Theatre (ATT) “combines creative arts workshops, performances, classes, leadership opportunities in an inclusive and expressive setting” (para 3). Performers in the Boston community occasionally visit the organization to lead group classes and rehearse lines with youth participants. Three of the main goals of the ATT project are to help youth with disabilities develop communication, artistic and leadership skills and cultivate lasting friendships (para 5). The ATT project urges youth participants to be actively and intimately involved every step of a theatre production just like The Miracle Project—making sets, acting, directing, making music and more. Not just allowing but *expecting* youth to be involved in every step of a production reinforces positive behavior and rewards risk-taking. One ATT participant states of their experience, “My words have

power... I have power” (Access to Theatre 2013). Another youth participant says of their experience, “You realize that you do have an effect on your surroundings, and you can make a difference. ATT has taught me lessons in patience, cooperation, teamwork, leadership and compassion” (Access to Theatre 2013).

There are a growing number of youth disability arts programs in the United States that foster the development of a positive disability identity utilizing a variety of different goals and practices. There are, however, criticisms that remain about youth disability arts and not only regarding the terminology used. Some arts educators have begun to wonder if youth disability arts programs should promote art making that allows the child to illustrate their experience feeling isolated or marginalized. Much of the artwork created by youth with disabilities already does illuminate certain experiences regarding personal challenges, but some of the work does not have to do with being disabled. While this seems expected, some are unable to view it as artistically progressive. According to Blandy in “Studies in Art Education” (1991), there is risk in defining artwork made by individuals with disabilities as “disability art” or limiting subject matter by disabled artists to deal only with disabilities because it can further marginalize those artists (p. 139). Still, there may be value in allowing room for youth artists with disabilities to create unashamedly, and without censor, communicating their thoughts in whatever media and subject matter they feel most appropriate. Art educators should applaud artwork that is difficult to express and made with utmost integrity, transparency and courage. As noted by Blandy (1991), displaying such work may be problematic. Perhaps particularly controversial artwork needs not be shown to the public. As art is a way to self-heal, to take risks, attempt personal goals and ultimately form a more positive

identity, then the creating of art far outweighs the value of displaying it. It is important for art educators to understand, as suggested by Sulewski et al. (2012), that emotion-driven artwork often feeds the strongest sense of positive identity development in youth (para 35). There are thousands of youth with disabilities nationwide who would greatly benefit from theatre and visual arts community programs. There is discrimination to overcome, but there is immense hope, and arts educators must forget neither sentiment.

According to Catalano et al. (2002), children establish their identities across many different contexts. Identity, he states, is a “structure of abilities, beliefs and individual history, shaped by the navigation of normal crises or challenges at each stage of development” (p 106). A child’s environment impacts the experiences they have and the opportunities that are available to them. The opportunity for youth with disabilities to express a positive identity is crucial in furthering developmental growth and aiding transitions into adolescence and adulthood. Youth with and without disabilities should have many opportunities throughout their childhood and adolescence to take part in arts projects. According to Blandy (1991), youth with disabilities can feel isolated or discriminated against in school arts programs or integrated community arts centers where their needs aren’t met and especially benefit from specialized programming (p. 134). For this reason and more, the existence of such programs as the Miracle Project, Access to Theatre on behalf of the Partners for Youth with Disabilities and the VSA Arts competitions are essential to the development of a positive disability identity in young people.

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