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Influencing Attitudes Toward People with Developmental Disabilities Using Arts Based Research

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INFLUENCING ATTITUDES TOWARD PEOPLE WITH DEVELOPMENTAL DISABILITIES USING ARTS BASED RESEARCH

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INFLUENCING ATTITUDES TOWARD PEOPLE WITH
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prepared by

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is approved in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Leadership and Change.

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Dedication

I dedicate this dissertation to my parents, Henrietta and Edward Goetz, who inspired me to live a life of continual learning, and to foster my creativity. Their support is invaluable, and I am the richer for their having lived and loved life, and their four daughters, so well.

Abstract

This study was conducted given as an inquiry about influencing attitudes toward people with developmental disabilities. Because resistance to homes for people with developmental disabilities situated in typical neighborhoods is still a problem, I seek a way to better assimilate people with "different abilities" into communities. For an historical foundation, I researched literature on the marginalization of this ethnographic group—people with developmental disabilities—and defined quality of life. In establishing groundwork for choice of methodology, I elaborate on arts used for social change. Arts based research methods were used to conduct the research. I created an exhibit using objects and photographs and words in a public space, intended to provoke thought and emotions. In order to evaluate the effectiveness, I used criteria outlined in *Arts Based Research* by Tom Barone and Elliot Eisner (2012), who indicate that the art piece should contain the following elements: incisiveness, concision, coherence, generativity, social significance, and evocation and illumination (p. 148). Findings affirmed that the arts-influenced installation successfully provoked and influenced attitudes toward people with developmental disabilities, as evidenced in written and oral responses. Implications for future research in this area of study using qualitative methods include: various arts based venues for research with other marginalized populations, participatory action research using the arts and many other provocative arts performances.

Keywords: arts based research, qualitative research, disability, marginalization, resistance, and quality of life.

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Chapter I: Introduction

Tolerance of difference does not necessarily lead to a mutual respect. A society in which one feels valued for cultural or individual characteristics creates room for constructive criticism for all parties involved. We all have the right to desire a satisfactory existence, a right for which we are all individually and collectively responsible. Accepting this common responsibility opens up the possibility to discuss and negotiate, on equal terms, the basic premises for a more just society (Essed & Goldberg, 2002).

Forty-three years ago, Title VIII of the Americans with Disabilities Act (ADA), as amended, The Fair Housing Act of 1968 (FHA), was passed in the United States, and yet this nation still has not enforced the rights of people with disabilities to be truly integrated into and to enjoy, fully, the advantages of their own community. Although this field has made strides in terms of the numbers of houses and individuals with disabilities living in the community, housing discrimination still appears in all forms and forums. Zoning codes exist that require public meetings wherein neighbors express their fear and rejection of the prospect of people with disabilities living in their community. Landlords who are not aware of the Fair Housing Laws still refuse to make reasonable accommodations, and some refuse to rent to people with disabilities. And realtors have been found to steer people with disabilities away from certain areas in which decent housing exists. Because these problems perpetuate years beyond the changing of the law, the barriers still exist for people with disabilities to equitably access their rights to live where they wish and to have an improved quality of life.

The divide between the current idyllic approaches to housing and resistance in neighborhoods concerns me. When placing people in a community setting, attempting to improve their quality of life, my colleagues and I in the field of special needs housing development hit up against the reality that this very model of scattered housing people with developmental disabilities creates community discontent on the part of neighbors, and therefore, isolation. In order to make a more seamless transition, I continually seek a way to influence attitudes toward people who have developmental disabilities. I chose an arts based research (ABR) method for this inquiry. According to McNiff, ABR is “the actual making of artistic expressions in all of the different forms of the arts, as a primary way of understanding and examining experience by both researchers and the people that they involve in their studies” (as cited in Knowles & Cole, 2008, p. 29). Through an art installation staged in a public setting, I endeavoured to stir emotions and prompt openness in the minds of viewers. By exposing the public to both the historical, inhumane treatment of people with developmental disabilities and positive images of people with disabilities through artwork, I theorized that viewers would experience some degree of enlightenment, whether small or profound. I wanted to see if participants viewing an exhibition that shows an ethnographic group’s experiences could influence their attitudes and lead to a new acceptance. I hoped to promote awareness and sensitivity to the rights of people with disabilities, so that they may live as you and I, in the home of their choice, and so that they may work and recreate in our community. I found that the presentation of societal treatment of a people did stir both visceral and intellectual responses. ABR can be a viable medium for social research and change.

Purpose of Study

In my professional work, that of developing single-family homes for three or four individuals with developmental disabilities, I often am confronted by neighbors who are concerned over the prospect. They express many fears, including lowered property values, threatened safety of their family, increased traffic on the street, to name a few. Most of these concerns are myths. First of all, many studies have proven that having a group of people living in a house in the neighborhood does not lower property values. Secondly, our tenants do not drive, so traffic is reduced to a couple of staff members coming to the house at certain times. Finally, and most difficult to achieve, is assuring neighbors that they and their families' safety is not at risk. It appears that fear of someone who is "different" is at the root of this concern. Some neighbors say to me, "But I have small children!" I have often surmised that fearful neighbors conjure a picture of a large male with mental retardation such as the character Lennie in *Of Mice and Men* (Steinbeck, 1937). Expressing his adoration, Lennie inadvertently squeezes the small animals to death:

> Lennie kills (a) puppy accidentally, as he has killed many mice before, by virtue of his failure to recognize his own strength. Although no other character can match Lennie's physical strength, the huge Lennie will soon meet a fate similar to that of his small puppy. (Steinbeck, 1937, Sec. 1)

Tragically, like an innocent animal, Lennie is unaware of the vicious, predatory powers that surround him. Like Lennie, our prospective tenants know not of this resistance.

Initially, people in the houses surrounding the new residence do not know the individuals who will be moving there, nor do most of these neighbors express an interest in understanding the people that may be living next door. The issues arise when they learn that a housing corporation purchased the home. At a Public Hearing, Harrison

Township, Montgomery County, Ohio, September 14, 2010, the following comments were heard from neighbors to the supported living homes established in this past year, 2010:

“Why did you not tell us you bought the house for this use? You snuck this in on us!”

“Don’t you have to get approval for a group home? We’ll meet with City Council about this!”

“I never would have bought in this neighborhood if I’d known there would be a home like this.”

“They don’t belong here!”

“Why don’t you just buy them a farm?”

Community resistance to inclusion in neighborhoods has its roots in perceiving people with disabilities as “other,” which comes from fear and ignorance of the unknown and uncomfortable. In 2006, Essed stated, in a lecture, “Other is perceived as a threat to the dominant norms and values.” Placing people out of sight was a solution for society from the 1800’s until the 1960’s, but this practice defiled the human rights of the exiled. This action of putting people out of sight because they are different delayed our maturation as a society. We cannot assume this happens easily, even now. And, although we have made strides with respect to integrating people of color, those who practice different religions, and gender preferences, and choice of partners, we have not yet evolved as a culture to an ideal point of full assimilation. Full inclusion would require acceptance of differences.

This dissertation research has offered me an opportunity to delve into a process of inquiry—ABR—that has broad potential in addressing the problem in my professional field.

“Arts based methodology is heuristic through which we deepen and make more complex our understanding of some aspect of the world” (Barone & Eisner, 2012, p. 3). Through a project in which an art installation depicts the history and current challenges of housing people with developmental disabilities, I have found that viewers, as participants, can be provoked to consider, contemplate, and feel about this social issue, and attitudes can be influenced, creating a more tolerant society.

Summary of Chapters

Beyond this introductory chapter, in Chapter Two, I initially share information on the historical treatment of this marginalized group and the movement to place people with developmental disabilities into community settings from institutions. I then describe quality of life descriptors, and lastly, I present the many genres of art used for social change. The movement of inclusive housing for people with disabilities and the factors of living in the community and improving quality of life are important issues to note. Therefore, I position the group of individuals with disabilities as an ethnographic group, moving from living in exile in institutions, to living in typical neighborhood homes. Changing residential settings improves lives tremendously, but a movement to improve the quality of life for people with developmental disabilities is imperative as the next step. I take the position that the arts offer rich opportunities for people to explore their creative selves, and as such, enjoy a greatly improved quality of life. The arts provide a voice with which people with developmental disabilities can express themselves so that they enrich their lives and can inform viewers about themselves. A wealth of expressive art by people with disabilities about the experience of living with a disability is emerging as this group discovers their voice in the use of art for awareness, so that they may enjoy their civil rights. As Crutchfield and Epstein state (2000):

> While disability has gained public and academic attention from these events and from the after effects of the Americans with Disabilities Act, questions of disability representation, access and identity remain. This area of inquiry constitutes the "undiscovered" territory of the late twentieth century. We write "undiscovered" with a note of irony, since these questions have been broached by disabled people since the beginning of time. (p. 3)

Following this principle of arts for people with disability, it seemed only fitting to design a certain coherence into my study by using arts based research to then influence attitudes of the public through my art installation. In Chapter Three, I strengthen the reasoning for using the methodology of arts based research to inquire about the potential for improving acceptance of people with developmental disabilities in neighborhoods. My research method involved an arts based installation about the treatment of people with developmental disabilities in the United States, including a variety of media. Staged in a public space, the display consisted of two-dimensional and three-dimensional art, sound, and visual media. Viewers were drawn to the display, to linger and absorb its message, and then were invited to comment on paper or to talk with me. Selected viewers were then interviewed, giving me an opportunity to document a deeper reflection and reaction.

Chapter Four contains the findings of the research. The results include field notes, comments, and interviews. The notes consist of research into the ethnographic group, a record of the process of project development, small conversations, and the responses to the installation. The second part consists of comments made by viewers, in person and on a pad provided at the end of the exhibit. Finally, in-depth interviews with selected participants were conducted after the research project was removed from public view. Scholarly resources, critique, and commentary are woven throughout the results chapter.

In Chapter Five, my analysis and discussion of data gathered during the exhibit is provided, and forms a basis for my interpretation. I discuss the current thinking in arts based evaluation among scholars, finally choosing the latest criteria from and Tom Barone and Elliot Eisner (2012). As evidenced in this chapter, I believe that the installation meets the criteria for arts based research set forth by these experts, and that these standards move the field forward.

Critical observations and implications of my research for leadership and change are discussed in Chapter Six. Also, recommendations are presented, making a case for using arts based research as a method of inquiry. Arts based research brings the researcher to the center of meaning, with its ability to reveal human understanding. As a research method, it joins “ethics, aesthetics, political praxis and epistemology” (Denzin, 2003, p. 258). The field of disability studies is growing as people with disabilities move beyond the political arena and establish an equal presence with a voice in our culture. There is much engaging and expressive work to be done in order to further this movement.

Definition and Use of Terms

Every field has a special language, so it is necessary to define key words, clarify select phrases, and offer history for the reader. Also, because semantics and phraseology can be politically sensitive, explaining the contextual use of terms will be helpful. As an example, throughout the dissertation, people first language is used, as in “people with disabilities,” rather than a “disabled person.” According to the Association for Retarded Citizens (ARC), “People-first language emphasizes the person, not the disability. By placing the person first, the disability is no longer the primary, defining characteristic of an individual, but one of several aspects of the whole person" (ARC, 2011). Similar phrases that are sensitive within the field are listed below.

Americans with Disabilities Act of 1990, as amended. In enacting the Americans with Disabilities Act of 1990 (ADA), Congress intended that the Act "provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities" (Americans with Disabilities Act,1990), and provide broad coverage; and in enacting the ADA, Congress recognized that physical and mental disabilities in no way diminish a person's right to fully participate in all aspects of society, but that people with physical or mental disabilities are frequently precluded from doing so because of prejudice, antiquated attitudes, or the failure to remove societal and institutional barriers.

Developmental disability. The term developmental disability refers to a condition that occurred before the age of 22 that resulted in substantial, functional limitations in key life areas. Major life activities include, but are not limited to: caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working. Causality (not always identifiable) includes: mental retardation, cerebral palsy, spina bifida, traumatic brain injury, and other injuries to the brain and spinal cord. Developmental disability is now used where the term "mental retardation" was generally applied to a person with a low Intelligent Quotient. Now recognized as offensive, and politically incorrect, the word, "retarded" is even considered, by some, to be hate language in the United Kingdom (World Have Your Say, 2011). The preferred clinical term for this particular syndrome is "Intellectual Disability." I use "developmental disabilities" in this paper to refer to the range of people who need support from our housing agency. Using "disabilities" refers to a broader group, including people with mental health and physical challenges.

The Fair Housing Act, Title VIII of the Civil Rights Act of 1968, as amended. Prohibits discrimination in the sale, rental, and financing of dwellings, and in other housing-related transactions, based on race, color, national origin, religion, sex, familial status (including children under the age of 18 living with parents or legal custodians, pregnant women, and people securing custody of children under the age of 18), and handicap (disability). (FHA, 1968)

Group home. A group home can refer to any group of people living together, including college students. In my business, a maximum four people share rent in a house with individualized services from a private agency. Describing a living situation in certain terms can lead to negative connotations. The term "group home" has become a label with a generalized understanding of who may live in the home.

Installation art. A generic term for "an art activity placed in a limited space within which or around which a communicative engagement is made, requiring varying degrees of activity/receptivity on behalf of the subject" (Bishop, 2005, p. 957). I have used "installation," "exhibit," "exhibition," and "display" interchangeably in this paper.

Self-determination. A concept that goes beyond the right to live in a decent home. This philosophy has driven practices and even law in Ohio and other states, requiring the incorporation of choice on the part of the individual. The American Association on Intellectual and Developmental Disabilities (AAIDD) defines self-determination for a person with a developmental disability as "having the same right to self-determination as all people and must have the freedom, authority, and support to exercise control over their lives."(AAIDD.org, 2011, p.1).

Supported living. (In the State of Ohio) "supports" are provided wherever the person lives, be it with their family or renting an apartment or home. Choice is a part of the legal definition in Ohio of supported living, for example, people choose where they want to live, who they live with, and who cares for them (Ohio Department of Developmental Disabilities, 2011).

Quality of life. Quality of life (QoL) typically implies well-roundedness and a sense of well-being. Recognizing the subjectivity of QoL is a key to understanding this construct. QoL reflects the difference—the gap—between the hopes and expectations of a person and their present experience. Human adaptation is such that life expectations are usually adjusted so as to lie within the realm of what the individual perceives to be possible. This enables people who have difficult life circumstances to maintain a reasonable QoL (Quality of Life Research Unit, 1995).

Positioning

"It is not necessary to know everything in order to understand something." (Geertz,1973, p.20)

It may be helpful for the reader to know a little bit about me, as applicable in this research. Figure 1.1 depicts the many roles and responsibilities that I balance in professional and personal life.

Figure 1.1

I have worked professionally in residential services for people with developmental disabilities for over thirty years. Having seen the conditions at what were then called “state institutions for the mentally retarded” after graduating from college, I saw that change was needed. My work has all been in the field of residential services. Currently, I direct a nonprofit housing corporation expressly for people with developmental disabilities; our mission is to create safe, affordable and accessible homes in the community for four or fewer individuals per setting.

I am an artist and I have obtained the degree of master of art therapy. Most recently, my having volunteered with young people with developmental disabilities at We Care Arts has affirmed for me the inherent value in the creative process. We Care Arts is a nonprofit organization that helps people with special needs and mental health challenges discover their natural gifts through the arts. It offers a safe “holding environment” where self-discovery can be pursued. Participants enjoy the nonverbal expression that can come forth through artwork at We Care Arts. Eisner (1998) states, “For feeling to be conveyed, the ‘language’ of the arts must be used, because it is through the form of symbol displays that feeling is given virtual life” (p. 28). Although not formally practicing as an art therapist, I have noted such joy in expression through the arts, for all participants. In addition to the joyful feelings, I have also found that people with developmental disabilities experience self-esteem enhancement, skill development, independence building, and the establishment of voice through making art. These benefits improve the participant's quality of life.

My journey into improving one's quality of life through creativity began long ago. As a young artist, I felt the therapeutic and life-altering sensation that occurs when one creates. The experience of creating catapulted me to a new level and a new view of my world and my position in it. In order to understand the phenomenon, I began to read about how the act of creating alters our sense of self. I read Rudolf Arnheim (1964), who reflected on our culture's understanding of the creative process. John Dewey (1934) wrote about art, experience, and fulfillment. Dewey was an early scholar of the creative experience. In lectures at Harvard University in the 1930's, Dewey wrote on the nature of art and human experience, noting that art provides "an experience in which the whole creature is alive and in which he possesses his living through enjoyment" (p. 27). One of the most important influences on me was Carl Jung (1964), who appealed to my creative side. Jung considers the creative drive as "innately common to all human beings" (p. 74).

I am a person without a significant disability; therefore, I have a *disadvantage* when it comes to true empathizing with the people for whom I work. For this empathy—this need to understand individuals' needs and desires—I primarily rely on firsthand information offered verbally or in written form from individuals; secondly, I rely on observation (watching someone navigate an entrance, for example), and finally, I depend upon professional advice from the person's aides or social service provider.

I have humbly approached this research project with complete respect for the individuals whose identity as a group I am exploring. As Clifford Geertz stated, “We no longer strain to read the culture of others over the shoulders of those to whom they properly belong.” (Geertz,1973, p. 32). Within the context of my professional position, I am the symbol, for some, of a *problem-solver*. For others, I am a *troublemaker*. Personally, I prefer to be liked and often strive to gain acceptance, so the notion of being the inflictor of pain is uncomfortable, to say the least. Some insight into how I dealt with this conflict came from reading Sumru Erkut (2001) in her book *Inside Women’s Power: Learning from Leaders,* she shared reports from women leaders who have developed comfort with risk and confrontation when fighting for a cause:

> The willingness to take risks in the cause of fighting injustice echoes back to many leaders’ view of their leadership as entailing responsibility for others. This same sense of responsibility that made them view being a risk-taker as a frivolous characteristic, also made them willing to take risks to fight for justice. In other words, when the focus of the leader is the well being of a constituency (either inside the organization or external to it in the form of a cause), one does not take risky positions without good reason. Fighting injustice is a good reason. (p. 66)

This rich experience of serving people with developmental disabilities in the most fundamental of ways—making homes—has been rewarding; however, I also ponder on whether or not the services and settings are really meeting peoples’ needs. The viewpoint from which I now look at this field positions me to enter into deeper introspection, and to embark on future research projects.

Scope of Study

Through arts based research, I conducted a research project in which my art installation offered education and enlightenment to viewers about the history and current experiences of a people: those who have developmental disabilities. My intent was to present a cultural understanding of the group, in order to publicly highlight the life experience of a people with developmental disabilities. In creating the installation, I gathered data from what I have learned about this marginalized group. I listened to people commenting as they viewed the exhibit. As a means of gathering viewers' responses, I was often present and listening at the exhibit. I also collected responses on a drawing pad, next to which I had placed colored felt tip markers for making comments. Then, I interviewed five selected participants. A descriptive account of the experience is described in Chapter 4, which includes research field notes that cover conception to conclusion of the research project and data collection.

This art exhibit coincided with March as Developmental Disabilities Awareness Month, a nationally recognized opportunity for advocates to stage publicity in the community. Annually, materials are produced in the form of posters, billboards, press releases, public service announcements, and events. My installation took place at the Montgomery County Administration Building in downtown Dayton, Ohio, from March 14 to April 1, 2011.

By exhibiting symbols, pictures, sound, and print, I presented a portrayal of lives in Ohio for a person with disabilities in the early 1800's, through the "deinstitutionalization movement" of the 1960's and 1970's, and into today's modality of housing people with disabilities in scattered settings of their choice in the community. I displayed the uncomfortable residential settings of institutions and the development of community living with its challenges of community acceptance, as well as positive images of life in the small community settings of today.

This qualitative study included data collection, described in multi-faceted ways, as follows: recording extensive field notes, observing viewers during the exhibition, and interviewing selected participants (viewers). The participants were the public, some of whom had not previously been involved with the services to people with disabilities. Throughout the process of creating the work, I gathered input from people with developmental disabilities, historical documents, and literature.

This was a study about a marginalized group and the public was learning about the experiences of a people; therefore, to maximize the human connection, both visual and audio media were used. Thusly, this dissertation is not only in written form but also contains media enhancements such as pictures and sound clips.

My ambitious endeavour to depict centuries of treatment, mistreatment, and the social movement to gain civil rights of a people in a single space and a few weeks' time had to be compressed into symbols, three-dimensional and two-dimensional representations, and text. The topic is broad in scope and yet it was simply logical to represent it in a timeline of a civil rights movement. This ethnographic group has been oppressed for centuries, and I wanted to portray the conditions in which they lived when placed in exile. A part of the exhibit showed life in an institution for "idiots" and "imbeciles," using four items: an old iron-framed bed, a window with bars, a wooden bench, and a set of three connected lockers. The vignette represented how life was inside an institution for over a century (1850–1970). The greater strides came after deinstitutionalization, in the 1970's, which was shown in pictures of group homes and print articles of community resistance. Flowing from a limited chromatic spectrum to full color, the viewer moved from seeing conditions of a restrictive past to seeing a brighter life in comfortable homes, nestled in typical neighborhoods. In spite of limited time, space, and funding, I was able to present a tale of a people. Important issues were revealed, a story of strife and freedom was told. And viewers were moved, as evidenced by the many comments that were recorded and those reflections that were shared in interviews.

Evaluation Criteria

In Chapter 5, I discuss how I believe this research project succeeded in meeting the criteria aforementioned. There exist, in scholarly literature, a number of evaluative criteria by which a research project is compared to standards. In order to evaluate my research in terms of effectiveness, I turned to Barone and Eisner (2012), who categorize criteria by which to judge arts based research:

> *Incisiveness:* The researcher gets to the heart of the social issue.
>
> *Concision:* The degree in which the work of art occupies the minimum amount of space and uses the least amount of verbiage necessary for it to serve its primary, heuristic purpose of enabling members of an audience to see social phenomena from a fresh perspective.
>
> *Coherence:* Features hang together as a strong art form.
>
> *Generativity:* The ways in which the work enables one to see or act upon phenomena even though it represents a kind of case study with an *n* of only 1. Also, its ability to promote new questions.
>
> *Social significance:* Thematic importance, its focus on the issues that make a sizable difference in the lives of people within a society. What one is looking for is something that matters, ideas that count, important questions to be raised.
>
> *Illuminating effect:* Evocation and illumination "…because it is through evocation and illumination that one begins to feel the meanings that the work is to help its readers grasp. … [Readers are] people who secure meaning in whatever form it needs to be read. Paintings are read, music is read, and dance is read. … Evocation is therefore an epistemological means for the acquisition of meaning." (pp. 149–153)

Chapter II: Literature Review

A review of the history and literature pertaining to three important areas is critical to the reader's understanding of this research project. As a practitioner in disabilities services, I will offer background on the history of residential settings and the remaining obstacles to assimilation into communities that people with disabilities face. In order to create the base for understanding the topic and method of inquiry, I will expand on three important areas:

1. History of people with developmental disabilities.
2. Quality of life issues for people with developmental disabilities.
3. The profound potential of social change through the arts.

History of People with Developmental Disabilities

This ethnographic group experienced a major shift in the move from an isolated treatment modality to one of integration into the community. I am witness to the fact that this shift is fraught with controversy because of the perceived differences. I believe that knowledge about people who are "different," because they have disabilities, will diffuse concerns and, ultimately, create better awareness and understanding so that true integration can occur. Such enlightenment can come through the use of the arts, which offer an array of emotionally evocative media, with the potential to inform, to present interesting encounters with the human in all of us, to result in assurance, and to ultimately help us to make connections.

The issues surrounding residential settings and treatment of people with developmental disabilities are profoundly about human and civil rights. The oppression and isolation that our society has imposed on the disabled parallels the treatment of other ethnographic groups that have been marginalized, whether due to race, country of origin, or gender, or peoples who are considered different. My observation of this marginalized group of individuals has been in Ohio, but treatment for people with all types of disabilities has been similar in each state. Although assimilation into the community is occurring at various levels, state to state, it has yet to be fully realized. Today, over 1,400 people remain in institutions in Ohio.

People with developmental disabilities who grew up in Ohio prior to the enactment of current laws that assure rights to all persons experienced oppression and isolation. In the United States in the 1800's, institutionalization was the accepted mode of treatment. The quality of life for individuals who were exiled from society was poor and inhumane. Trent (1994) traces the history of treatment of people with mental retardation from a time when families either took care of (or hid) their relatives with obvious disabilities, to the era when doctors recommended placing babies who had delays or were blind in state schools for the blind and deaf. By the early 1900's, institutions bulged with people who had a wide array of disabilities. They were kept distant from civilization's gaze. In 1903, the population in state institutions in Ohio was over 14,000. The thinking of the day was: "Total institutionalization kept mental defectives safely in the confines of the institution so they would not be a menace to society" (Trent, 1994, p. 142).

Superintendents of these albatrosses were motivated to convince the public of the necessity of the institution. The Committee on Provision for the Feeble-minded held a conference in which E. R. Johnstone called for "greater efforts (to) be made to have the great public know of the defectives… We must conduct a campaign of education, so that in the first place the unwillingness of parents to send their children shall be changed to eagerness." (Johnstone, as cited in Trent, 1994, p. 170)

By 1910, most institutions were so large that the respective superintendents had little contact with inmates. Trent (1994) describes the low standard of attention given to residents:

> Institutionalization itself did not insure a community of caregivers and care receivers. The demands placed on institutions to take more inmates with more diverse and often-complex problems inevitably found its consequences in increasing burdens for attendants. The attendant, not the educator or the physician, was, in fact if not in rhetoric, the most crucial actor in the lives of inmates after 1890. Care, not education or treatment, had become the central focus of institutions by the turn of the century, and attendants…were the principal caregivers. (p. 129)

Families, who believed doctors' and teachers' recommendations that the best place for their family member was the institution, remained hopeful as expressed in these excerpts from letters from parents:

> How is little Grace? Doesn't she chill these mornings? Put on little shirts with long sleeves if it continues cool and damp. Dress her warm, Dear, and don't be too hard on her for she is a mamma's baby. Beverly Farms Records, letter to Instructor of the Girls' Department, 21 September, 1917.
>
> Will you find out if Sammy is in need of anything and let me know? Also, will you see if his shoes are big enough….I don't want the child to suffer. If you will do that for me I will appreciate it very much. I miss him so, and often wonder if those little details are noticed. Wonder if he misses his mama. He loved me so much it seems a pity to put him away. Is little Sammy learning to talk or is he just the same? Sometimes I still have hope for him although I know it is useless. Beverly Farms records, letter from 1914. (Trent, 1994, p.113)

The movement to free people who had been confined to an existence on large wards with little human attention or family involvement proved to be inspiring to a young idealist such as myself. I followed the tenants of a German immigrant to America, Wolf Wolfensberger (1972), who is the author of *The Principle of Normalization in Human Services* and other thoughtful books on people who are disenfranchised from the social norm. I had heard him speak at a conference of the American Association of Mental Retardation in 1978. Attendees of the Conference in Miami, Florida, at the Fontainebleau Hotel were young and ambitious like me. We had found an “indirect leader” and change agent (Gardner, 1995). Wolfensberger coined the term “normalization” and set a course for what we knew needed to be done: move people out of institutions. This came to be known as *deinstitutionalization*. Individuals who had been isolated and sometimes treated like animals were moved out into community housing to enjoy a “normal life.” Wolfensberger made an impact on professionals in the field and people whose lives were changed forever. Howard Gardner, in his book *Leading Minds* (1995), described an indirect leader as “an individual (or rarely, a set of individuals) who significantly affects the thoughts, feelings, and/or behaviors of a significant number of individuals,” and does so without having the title of an official leader (p.113).

The term “normalization” has always given me pause. What is the standard “norm” that would serve as a compass for assimilation? A presumption was also made that an ideal is that of assimilation into the greater culture, and that people with mental retardation would choose this integration, if they could choose to do so cognitively. Wolfensberger (1972) defines normalization:

> Normalization is the provision of patterns and conditions of everyday life for the mentally retarded, which are as close as possible to the patterns of the mainstream society. Reformulated in this treatise, normalization should aim at personal behaviors and characteristics, which are as culturally normative as possible, and arrived at through the use of culturally normative means. Thus, a deviant person should be helped to look and behave in a way appropriate for that culture for persons of similar characteristics such as age and sex. Normalization involves interaction with others. Contact occurs at three levels: 1) with individuals; 2) with primary social systems such as the deviant’s family, peer group, classroom, school, neighborhood, and place of work; and 3) with the

> relevant societal social systems such as the school system of a province, the laws of the land, and the mores of a society. (p. 27)

Wolfensberger’s proposition in 1972 was ideally timed for a revolutionary change in the way people with mental retardation were treated in many states, including Ohio. The isolation of people with disabilities from the mainstream had been the answer for both families and society to address the question of how to treat people who are disabled. But in the mid 1970’s, lawsuits began to be filed in each state in the United States by parents and advocates over the denial of institutionalized individuals’ civil rights. This set in motion a movement to close institutions and reintroduce people into their cities and small communities of origin—into group home settings in single-family houses. Opportunities then arose for new local social service agencies to open businesses providing residential and day program services to people with disabilities.

In the 1970’s, the quality of care of inmates of institutions was dramatically exposed on television by Geraldo Rivera (1972). Letchworth Village and Willowbrook State School were filmed by Rivera (1972), and he called it “the last great disgrace” Trent, 1994, p. 229). The public saw the dramatic picture, and the public’s reaction was palpable. But it took the legal actions of advocacy agencies, such as the Ohio Association for Retarded Citizens, for real change to occur. In order for deinstitutionalization to begin to take place, laws were enacted as a result of lawsuits that stressed the “least restrictive environment” for each individual. In many cases, group homes were less restrictive than institutions. Therefore, most of the “inmates” of institutions were sent to their home counties and placed in group homes of eight to twelve residents. Owned and operated by start-up provider agencies, these homes were licensed for a certain number of beds. If an individual moved out, the bed was back filled, and the person was forced to give up his/her funding for care.

For professionals who latched onto the philosophy and work of deinstitutionalization, group homes nestled in typical neighborhoods were a positive change. However, to the neighbors, the proposition was commonly unacceptable. Much resistance occurred in public and in private. Zoning barriers were insurmountable in some jurisdictions; neighbors of sited group homes sometimes resisted so effectively that delay and sometimes denial of successful openings occurred. Battles are still occurring over zoning codes. Unfortunately, the acceptance of any size group of people with disabilities living in a house in the community is still more a rarity than it is common.

Not only were communities unprepared for group homes, but also some families of the individuals did not know about the movement of people back to their home county. Mass movements took place in short periods of time. When I described my idea for this research project to a retired colleague, a former case manager, she thought back to a disturbing memory. “I remember like it was yesterday,” Nyra said as she shook her head. She paused to tell the story of her day in a courtroom to which she had been subpoenaed. The State of Ohio had been charged with “dumping” people in Southwest Ohio without informing the families of pending moves of their relatives from the two institutions they had resided in most of their lives. Ohio Legal Rights, an advocacy agency that was governor appointed as a part of Ohio Senate Bill 336, had called the state to task. As a result of the lawsuit, more careful notice was mandated. Nyra recalled a trembling fear, as she was to testify about her working in the deinstitutionalization movement. “I watched them lie, and tell the judge that the families had been notified," she said of her supervisors. She had sworn to herself that she would tell the truth about mass moves, and the lack of notification to families, but that may have meant being fired because she would be stating events counter to her boss's account. A wave of relief came over her as the judge dismissed the hearing and never called her back to the courtroom. She and her colleague celebrated with a stop for ice cream along the drive home to Dayton. She reported being able to then breathe more easily, and continue her work of case management.

Since the mid-1970's, the United States has made great strides in improving the lives of people with developmental disabilities, but we have not yet "arrived." Lawsuits filed by advocates and parents in state after state began to require that educational programs be offered to each individual, and also that each person be moved to a residential program which is the "least restrictive environment" for them. In Ohio, Senate Bill 336 contained this language. This law turned the workers of state institutes into "habilitation specialists." I recall a day in 1977 when social workers made rounds to each resident of the Columbus State Institute, and asked individuals to sign a paper that became their ticket to freedom. The consent form dissolved the status of the individuals as "wards of the state" and established each resident as *voluntarily committed.* Unless a probate court judge sentenced an individual to the institution, these people were free to leave. Of course, few understood what they were signing or the implications. But the signed form freed the state to discharge people to their home communities without further consent.

Presently, "Supported Living" is the accepted model of housing development, and it consists of smaller groups of people who live as a family in a home or apartments located in the community. Funds are attached to the individual from Medicaid, a federal program that is designed by each state, and local funding match is provided through property taxes. This Medicaid program provides portable waivers, allowing “free choice of provider.” An individual who is not happy with his/her caretaker can release them and hire a new provider, and stay in place. Choice is incorporated into the law in Ohio, and the state and respective counties are mandated to assure that individuals have the opportunity to choose their own providers. Giving people choice is a step toward giving people voice.

Neighbors of people with disabilities often object to the scattered housing within the supported living model; thus, we have not yet reached true integration of people with all abilities. Full assimilation has not occurred, as evidenced by resistance to people living in single-family neighborhoods, issues of transportation and access remain. The general quality of life of individuals with disabilities is not impaired by these conditions. Therefore, the movement toward acceptance in the community must maintain momentum. Moving from the basic need for decent shelter to access to socialization in the mainstream, and ultimately, to the allowance of full expression and “self-actualization” (Maslow, 1943) will allow individuals with all kinds of disabilities to improve their ability to live a full life.

During the deinstitutionalization phase, the presumption was this: if the setting were in a residential neighborhood, the residents would be part of the neighborhood eventually. In my work of renting to people with developmental disabilities, I note that they seem happy living in nice houses with their own bedrooms, and they are less isolated than in the institutional setting. Neighbors in these settings, however, do not typically mingle with our tenants. In fact, some neighbors have telephoned me to challenge the legality of the people with disabilities even living in a small group (four or fewer) in a house in their neighborhood. The callers are not always calm. I have found that the act of listening to a complaint often has a diffusing effect. Nichols (1995) notes that, in an emotionally charged exchange, “A speaker who expresses himself or herself in a highly emotional way makes listeners anxious and therefore hard of hearing” (p. 98). Sitting with my own passion about the rights of individuals to live well, and my ownership of having chosen and bought that house in the caller’s neighborhood, I need to move into a listening mode. After I let the speakers express their concerns, I thank them and mention that I appreciate their calling me, and then I explain our program. It seems that when some tension is released, fears are allayed. In the best cases, the neighbor eventually relates as a good neighbor with our tenants; in the worst cases, surrounding homeowners and even renters gather together with a collective voice of resistance and raise concerns to local elected officials, and the home opening is delayed and/or the tenants are continually harassed. During such challenges, discriminatory words are often used in the discourse until the home is opened. I suspect that some neighbors resign themselves to the fact that the home next door is occupied by people with disabilities, and that there is nothing they can do to change the situation.

The identification of mental retardation as different and frightening is cultural. Hank Bersani (1987), professor of special education at Miami University in Ohio, states that “societal perceptions of individuals with mental impairments have meaning only within a specific cultural milieu” (p. 242). Positing people with disabilities and specific disabilities such as retardation in a specific societal context broadens the lens to show us that all issues and people are considered *in context*. And the context of the experience of a marginalized group is within the ethnic group's era, geographical location*, and culture.* Additionally, the society whose history has been to exile those who are different needs to be at an evolutionary point at which that society is open to change. Therefore, with respect to accepting Wolfensberger's (1972) movement to "normalize" people with mental retardation who had lived in institutions, contextual presumptions included the following considerations: first, that people with mental retardation were isolated in western culture; second, that the individuals who were disengaged from society would have wanted to be included in life with their families and neighbors and living like the rest of society (societal "norm"); and finally, that the general public would be able to assimilate the formerly isolated population.

Large group homes were the acceptable mode of housing people who were deinstitutionalized in the 1970's and 1980's until supported living came into vogue. The latter model requires that no more than four individuals live in a home. Here in Ohio, local battles continue in arenas such as zoning and neighborhood acceptance. Although the federal legislation has been in effect for decades, and people have been moving into homes nestled in residential areas, almost every house that I purchase for housing people with disabilities prompts challenges from surrounding homeowners.

In my quest to find a solution to the challenge of prompting better acceptance of people with disabilities in community settings, I have collaborated with other support organizations, such as the Miami Valley Fair Housing Center (MVFHC). Cohen, Vega and Watson (2001) speak of such parties as "Social Movement Advocates, "whose actions are defined as: Giving voice to critical yet unmet public needs, often those affecting women, poor people, indigenous peoples, ethnic minorities, people with disabilities, workers and the environment" (p. 13). They defend the rights of all people to live in a home of their choice. We collaborate with each other and with the officials in the county, including: the Montgomery County Board of Developmental Disabilities, Montgomery County Community Development, and each jurisdiction within the county (cities and townships). The MVFHC has studied the 28 zoning codes in the Montgomery County and found that two thirds of them were out of compliance with the Fair Housing Act. Therefore, the group has embarked on a plan to encourage and assist jurisdictions in changing the language in the local land use codes. Federal law is clear: "It is unlawful for local governments to utilize land use and zoning policies to keep persons with disabilities from locating to their area" (Fair Housing Act, 1968, amended 1991). Additionally, jurisdictions that receive federal funding for the improvement of infrastructure must agree to practice fair housing, and when called on regarding a denial of civil rights in housing, the jurisdiction may lose federal streams of funds such as Community Development Block Grants (CDBG). The MVFHC not only initiates change, but goes beyond that to push for citizens' rights through an array of legal avenues, including: filing official appeals on behalf of the citizens or agency experiencing discrimination, entering into civil law suits, and filing complaints with the Ohio Civil Rights Commission.

Admittedly, laws, policy, and funding are necessary and carry muscle in order to force change; however, I wish to address issues of attitudes of acceptance. When my agency obtains funding, we customize a house or an apartment building and proceed to rent to the individual with disabilities. It is when neighbors object to the use of the property that the issue of acceptance becomes my challenge. As representative of the nonprofit housing corporation, I have waded through bureaucratic red tape, public hearings, meetings, and encounters with angry neighbors. Occasionally, we have been denied approval to open a home or build an apartment building. But when this astounding event occurs, and basic civil rights to live in decent housing is denied, then a large balance of my time and energy necessarily goes toward the legal and social issues of fair housing.

According to The Fair Housing Amendment of 1988, in the United States people can choose where to live, given economic ability. The amendment clarified cases of discriminatory zoning or acts in housing. The law states that requiring special provisions, such as a “Conditional Use Permit” for people with handicapping conditions is discriminatory. The Fair Housing Act makes it unlawful to:

- Utilize land use policies or actions that treat groups of persons with disabilities less favorably than groups of non-disabled persons. An example would be an ordinance prohibiting housing for persons with disabilities or a specific type of disability, such as mental illness, from locating in a particular area, while allowing other groups of unrelated individuals to live together in that area.
- Take action against, or deny a permit, for a home because of the disability of individuals who live or would live there. An example would be denying a building permit for a home because it was intended to provide housing for persons with mental retardation.

- Refuse to make reasonable accommodations in land use and zoning policies and procedures where such accommodations may be necessary to afford persons or groups of persons with disabilities an equal opportunity to use and enjoy housing.

The Fair Housing Act prohibits discrimination on the basis of handicap. "Handicap" has the same legal meaning as the term "disability" which is used in other federal civil rights laws. Persons with disabilities (handicaps) are individuals with mental or physical impairments that substantially limit one or more major life activities. The term mental or physical impairment may include conditions such as blindness, hearing impairment, mobility impairment, HIV infection, mental retardation, alcoholism, drug addiction, chronic fatigue, learning disability, head injury, and mental illness. The term major life activity may include seeing, hearing, walking, breathing, performing manual tasks, caring for one's self, learning, speaking, or working. The Fair Housing Act also protects persons who have a record of such impairment, or are regarded as having such impairment. (Fair Housing Act, 1968, as amended, 1991).

The Miami Valley Fair Housing Center assists individuals and agencies in enjoying their full civil rights. Because it is illegal to discriminate against people with disabilities in housing, when a jurisdiction (city or township) asks an agency to apply for a zoning variance, the local Fair Housing Center requests “Reasonable Accommodation” due to the individuals’ disabilities under Americans with Disabilities Act and The Fair Housing Act. Although the federal law stands, some jurisdictions still have antiquated zoning codes that may illegally require an agency such as my housing corporation to “jump through hoops” in order to provide the needed housing.

Title VIII of the Civil Rights Act of 1968 (Fair Housing Act), as amended, prohibits discrimination in the sale, rental, and financing of dwellings, and in other housing-related transactions, based on race, color, national origin, religion, sex, familial status (including children under the age of 18 living with parents or legal custodians, pregnant women, and people securing custody of children under the age of 18), and handicap (disability). (The Fair Housing Act of 1968, 42U.S.C.A. §§ 3601-3631).

As we take stock today, in 2011, we realize that the rights of people with disabilities are still being challenged on local levels—in city hall, neighborhood association meetings, and in backyards. So, the civil rights movement of people with disabilities continues, and I join self-advocates in working toward individuals rights to freedom to live, work, recreate, worship, and fully celebrate life.

Quality of Life for People with Developmental Disabilities

After many years of working to improve living conditions for people with developmental disabilities by developing community-based homes, my focus is now on the improvement of quality of life (QoL) for people with developmental disabilities. I present the concern for quality of life in regard to this research because it is crucial for success in living in community. We cannot presume that placing people in four-person settings in a suburb will help to integrate people any better than placing them in eight- or ten-person group homes. Socialization, which is a contributor to a good quality of life, does not necessarily follow the relocation of people's homes. I discuss elements for improved quality of life in the residential setting—belonging, becoming, and creating—and elaborate on how creating can contribute to improving quality of life for people with developmental disabilities.

QoL is a term used in the medical field and in aging services, and now has recently entered the arena of services for people with disabilities. QoL may be defined as the degree to which a person enjoys all of the possibilities of his/her life. Possibilities result from the opportunities and limitations each person has in his/her life and reflect the interaction of personal and environmental factors. Enjoyment has two components: the experience of satisfaction and the possession or achievement of some characteristic, as illustrated by the expression "She enjoys good health." Three major life domains are identified: first, *being*, then, *belonging*, and finally, *becoming*. Following is a description of the three elements in considering Quality of Life from the Quality of Life Research Unit, University of Toronto:

Being. Is the whole person with three balanced aspects: physical, psychological, and spiritual. The being domain includes the basic aspects of "who one is" and has three sub-domains. Physical being includes aspects of physical health, personal hygiene, nutrition, exercise, grooming, clothing, and physical appearance. Psychological being includes the person's psychological health and adjustment, cognitions, feelings, and evaluations concerning the self, and self-control. Spiritual being reflects personal values, personal standards of conduct, and spiritual beliefs which may or may not be associated with organized religions.

Belonging. Includes the person's fit with his/her environments and also has three sub-domains. Belonging to a community is a dimension of QoL that housing agencies can begin to create by opening doors to community living. The location of one's home is pivotal to accessing opportunities for physical, social and community belonging. However, community acceptance has not been fully achieved for people with disabilities; therefore, more work on awareness is needed to promote the understanding that people with disabilities are to be afforded all the rights and privileges of all American citizens. These rights include living in a home, near work, friends, places of worship, and social involvement.

Physical belonging is defined as the connections the person has with his/her physical environments such as home, workplace, neighborhood, school and community. Social belonging includes links with social environments and includes the sense of acceptance by intimate others, family, friends, coworkers, and neighborhood and community. Community belonging represents access to resources normally available to community members, such as adequate income, health, and social services, employment, educational, and recreational programs, and community activities.

Becoming. Refers to the purposeful activities carried out to achieve personal goals, hopes, and wishes. Practical becoming describes day-to-day actions such as

> domestic activities, paid work, school, or volunteer activities, and seeing to health or social needs. Leisure becoming includes activities that promote relaxation and stress reduction. These include card games, neighborhood walks, and family visits, or longer duration activities such as vacations or holidays. Growth becoming activities promote the improvement or maintenance of knowledge and skills. The creative process provides a person with an opportunity for self-expression, which both affirms the self and opens an individual to experiencing new realms. *Becoming* can also be cultivated using the creative process. (Quality of Life Research Institute, 1995)

Understanding the human experience in total, including our creative side, helps us to realize that individuals creating art of any form, regardless of intellectual capacity, can experience personal enhancement, joy, and often a change in perception during and following the act of being creative. Even as a student in high school, I sensed the value of being creative, which can bring deep insight, improve well-being, and provide catharsis as well as a sense of accomplishment. Dissanayake (1988), in her thoughtfully provocative book entitled *What is Art For?* observes that when embellishing an idea or object with intention, bringing the creation out of the everyday, and enhancing it to become a unique creation, artists and perceivers both experience the *special* nature of the new piece. She calls this experience “making special” (p. 92). The activity of “making special” can be seen in ancient human artifacts, nineteenth century paintings, twentieth century orations, traditional song, contemporary music, and tales across the ages. Anywhere humans originated or altered an object with deliberateness, Dissanayake notes, someone was “making special.”

These examples of the very positive effect of creating prompted my interest in the growing field of art therapy. Howard Gardner, in his book *Creating Minds, An Anatomy of Creativity as Seen Through the Lives of Freud, Einstein, Picasso, Stravinsky, Eliot, Graham, and Gandhi* (1993), speaks of creative human activity as “conceiving, articulating and responding to ideas” (p. 7). He notes that with energy and commitment, the creative individual *defines* him/herself through his/her work. Although the work may never be famous, and the creator may never be noticed, the individual who creates can feel fulfilled. Giving people with disabilities opportunities for fulfillment through the arts would be making a significant step toward improving the experience of life. Furthermore, the arts can help an individual to reach a higher level of existence, as theorized in Maslow's *A Theory of Human Motivation* (1943). Maslow developed his model of human needs from basic food and shelter, moving levels up to emotional, then social, and peaking at "self-actualization."

The vibrant program in this Southwestern Ohio Region—We Care Arts—is an experiential center open to anyone who wants to connect with others in an expressive environment. It is one of many such places where people with disabilities can go to express themselves with guided experiences. At We Care Arts, there is a strong sense of belonging among attendees. The Art Café is a regular Tuesday program for people with developmental disabilities that offers a supportive environment, with activities such as painting, crafts, and music. Very popular and well attended, Art Café allows a person to work on an individual project while enjoying socialization. Maintaining connections in the community is important to individuals and their quality of life, as highlighted in the University of Toronto model. An individual who is nonverbal yet uninhibited and untainted by formal art training can find great joy and sense of self in art expression. "For feeling to be conveyed, the 'language' of the arts must be used, because it is through the form a symbol displays that feeling is given virtual life" (Eisner, 1998, p. 4).

I believe that the creative process also prompts people to become more self-aware. This increased self-awareness leads to confidence, which in turn can lead to increased and/or more successful interaction with others or socialization.

Figure 2.1 Paul enjoys the Art Café every Tuesday evening at We Care Arts

Similar programs exist elsewhere in Ohio, such as the Open Door Art Studio in Columbus, and even worldwide, such as King Street Artworks in New Zealand, a creative space for people who use, or have used, mental health services, as well as their friends and the community. Its aims are to “promote well-being in the community through creative expression, placing *whanaungatanga* (family togetherness) at the heart of what we do” (http://www.artsaccess.org.nz/)

Mihaly Csikszentmihaly (1996) believes that the concept of creativity is fundamental. Therefore, anyone can partake. As a psychologist who researched at the University of Chicago, Csikszentmihaly wrote that creativity is about capturing those moments that make life worth living. He states, “To have a good life, it is not enough to remove what is wrong from it. We also need a positive goal, otherwise, why keep going?” (p. 11). He points out that creativity provides an exciting model for living. In his book *Flow, the Psychology of Optimal Experience* (1990), he tied the creative experience to the concept of “flow.” “The flow experience,” he writes, is “the way people describe their state of mind when consciousness is harmoniously ordered, and they want to pursue whatever they are doing for its own sake” (p. 6). Csikszentmihaly coined moments of “optimal experience,” as the exhilaration that one feels during creative endeavors. These “optimal experiences,” the state of fully enjoying the moment, he points out, richly improve quality of life. Using a qualitative method he calls “experience sampling,” which entails interviewing individuals with questionnaires in a random pattern throughout each day for a period of weeks, Csikszentmihaly (1990) gathered a body of data about how people feel during various activities. His research revealed that enjoyment occurs when the following eight major elements are met:

1. We confront something we know we have a chance of completing.
2. We are able to concentrate on what we are doing.
3. The task we are confronting has clear goals.
4. The task provides immediate feedback.
5. We act from a deep, effortless involvement that removes worry and frustrations of daily life.
6. Concern for the self disappears, yet paradoxically the sense of self emerges stronger after the flow experience is over.
7. Control is allowed over the environment.
8. The sense of duration of time is altered. Hours pass by in minutes and minutes can stretch to seem like hours. The combination of these elements causes a sense of deep enjoyment that is so rewarding, people feel that expending a great deal of energy is worthwhile, simply to be able to feel it. (1990, p. 49).

Social Change Through the Arts

I propose that awareness about people with disabilities can come through the use of the arts, which offers an array of emotionally evocative media with the potential to inform, present interesting encounters with the human in all of us, result in assurance, and ultimately make conscious and unconscious connections. If we all understood and related more to people who seem to be different, we could develop awareness and ease integration. I chose to research the potential of the arts and the potential for social change in community acceptance. I turned to resources on the arts in research. Knowles and Cole (2008), in their *Handbook of the Arts in Qualitative Research*, *Perspectives, Methodologies, Examples, and Issues*, describe the purpose of arts informed research: "To enhance understanding of the human condition through alternative (to conventional) processes and representational forms of inquiry, and to reach multiple audiences by making scholarship more accessible." (p. 59).

Knowles and Cole list necessary elements of arts-informed research:

- First and foremost, involving a commitment to a particular art form(Containing) methodological integrity.
- The creative inquiry process (possesses) openness to human imagination.
- The subjecting and reflexive presence of the researcher is evident in the research text.
- Has strong reflective elements that evidence the presence and signature of the researcher.
- Relates to (the) audience.
- Is explicitly tied to moral purposes of social responsibility and epistemological equity. (pp. 61,62)

Different modes of art can be used for research. In fact, as McNiff (1998) states, "One of the most valuable features of art-based research might be its potential for offering very different ways of approaching the most serious problems that we face, in the world, today" (p. 37). Regarding variety in arts mediums, the award-winning filmmaker Silvia Hamilton (Cole, 2004) quotes from film-maker Lorri Neilson:

> I don't think one form should be accorded special privileges over others, or should dominate. There is rigor in all forms, and we have to judge them within their own framework. If we're looking to create forms of knowledge that others might consume, or engage with, we can't assume that everyone engages through the same. (p. 115)

Many genres of art for social change are available and some have been successful. The disability community has used performance in the form of protest to increase exposure to people with disabilities to the public. Disability rights advocates have held rallies, sit-ins, and other demonstrations to advocate for full access (to buildings, jobs, and housing). Popular culture, especially television, has helped the general public become aware of people with disabilities through casting people with obvious disabilities, such as people with Down's syndrome or people who use wheelchairs. And social media is a new venue for communication. I highlight, below, a sampling of a variety of media through which social change can occur, with potential for sharing information about people with disabilities.

Social Media. Social media is exploding with information by and for people with disabilities. There are many examples on YouTube, such as the Empowered Fe Fes, a peer group of young women aged sixteen to twenty-four with different disabilities, who reveal a very personal area of their lives when they talk about sex and disability. The general public, while "surfing the world wide web," stands to be enlightened by websites such as these. Again, interest must come from the seeker when browsing social media. Public awareness hinges on exposure to the real life experiences of people with disabilities. Ruth Behar makes the point that even in a contemporary world of multimedia resources for informing and unlimited entertainment, ethnography is still sought out as a “necessary way of knowing” (as cited in Knowles & Cole, 2008, p. 530).

I sought representations in social media of visual art that promoted social awareness and change because my background is in the visual arts. Visual and other expressive arts *for* and *by* people with disabilities are found via Google sites. Mining by the search words “art for people with disabilities,” I found the following sites: http://www.e-bility.com/links/arts.php, where there are sites to events worldwide; many in Australia (http://www.artsaccess.com.au/), New Zealand (http://www.artsaccess.org.nz/); the United Kingdom; and parts of the United States, such as the San Franscisco-based program Creativity Explored (http://www.creativityexplored.org/).

A wonderful website based in the Netherlands, http://artforsocialchange.net features works by Rini Hartman, visual artist. Rini uses drawings, photography, and other print techniques to produce postures for global awareness of people and plights. She pictures women who are struggling in Africa, and environmental awareness. All proceeds from sales of posters go to the United Nations Millennium Development Goals Project. Rini presents her philosophy on the site http://www.rinihartman.nl: “A belief in cultural and creative expression as a means to affect deep and lasting social change. Through art, we can challenge many of our society's deepest assumptions, built upon the power of artistic creation and expression to: ‘spark new ideas, catalyze critical thinking, elicit new actions, inspire individuals and create visions’” (Hartman, 2010, p.1). In an effort to encourage change in legislation, Rini has coined her efforts as “creative lobbying"; art becomes a political act, a conscious effort to facilitate and participate in social change.

Narrative. Narrative has always been a means of sharing stories and increasing awareness of the experiences of others. Storytelling is art based research in the writing genre. Heather Forest (2007) published her doctoral dissertation on storytelling's creative process. She writes of the experience:

> Utilizing art making as an inquiry method, I mindfully became an *embodied research environment* during this study…Through a literary, autoethnographic writing process, I observed, described, interpreted and named the steps in my creative process as I designed, rehearsed and performed an original storytelling work. (p. v)

Forest (2007) describes storytelling as a reflective practice, but she has done so in tandem with audience response, which influences the performance. Imagine storytelling performed by people with developmental disabilities, to an audience that is learning about the individuals performing. This would be a powerful way to share awareness.

An example of narrative that was in the form of an exhibit first is *The Lives They Left Behind* by Darby Penney and Peter Stastny (2008). The exhibit was of a variety of items found in suitcases left in an attic after the institution closed in the 1980's. The exhibit and subsequent book told the story of ten people who had been institutionalized for most of their lives, but the interesting angle is that these stories were created post mortem. These individuals had been put in state institutions for having mental health issues or other syndromes that society did not tolerate in the public arena. The poignant photographs by Lisa Rinszler contribute to the reader gaining a sense of "knowing" the men and women, about whom the researchers had learned.

Maxine Greene (1995) has been writing essays on art for social change for decades. Her enlightened writings move the reader out of their comfort zone into an open-minded world of creative imagination, education, arts, and social change. A renowned educational philosopher, author, social activist, and teacher, Dr. Greene is a sage on the arts and social change, especially in the area of art in education. She wrote valuable suggestions on creating awareness of people who have been marginalized in the past. In her book, *Releasing the Imagination Essays on Education, the Arts and Social Change*, she describes pluralism and multiculturalism in educating young people:

> Americans have wondered how to reconcile the impassioned voices of cultures not yet part of the whole with the requirements of conformity, how not to lose the integrity of those voices in the process, how not to allow the drive to conformity to determine what happens in the end…. It is a community attentive to difference, open to the ideal of plurality. That which is life affirming in diversity must be discovered and rediscovered, and what is held in common becomes always more many-faceted, open and inclusive, and drawn to untapped possibility. (p. 167)

Schools. Public and private schools can teach effectively about disabilities, and inclusion has helped toward acceptance. Educational research resources result in more awareness efforts, including curricula. In research, Beart, Hardy, and Buchanan (2005) found that students' attitudes were altered positively through a curriculum about people with disabilities in their article, *How People with Intellectual Disabilities View Their Social Identity: A Review of the Literature.* Beart et al. noted that more studies are needed of this sort. Having found this encouraging report on the effects of an awareness program on attitudes of students without an intellectual disability towards persons with an intellectual disability, I was further inspired to create this installation to improve public awareness.

Public venues. As a result of increased accessibility, the public sees people with disabilities shopping and attending arts events, for example. People with disabilities are working in your local grocery store, at Goodwill Industries and other sheltered employment. Handicapped accessible signs are now installed where legally required. These signs allow people to park, access buildings, and to use restrooms in public places. The Americans in Disabilities Act requires accessibility in public spaces; however, more awareness efforts are needed for full assimilation.

The arts used for social change has the potential to share powerful messages that result in an expanded awareness about the experiences of others. In this research, I have observed that art can help improve awareness of people with developmental disabilities and prompt a better understanding by the community. As promisingly put by Hodges, Keeley, and Grier (2001):

> Works of visual art provide a means of engagement with images and subjects that may sensitize the viewer to human experiences depicted by the artist. It is this engagement that fosters recognition, understanding, and the potential for shared meaning. Clinically, the image bridges the gap between the limitations of language and experience. (p.390)

Viewing art, as well as making art, moves people of all abilities. Elaine Scarry (2001) recognizes the effects of creative acts on an observer, noting that creativity does not end with the one who creates. Speaking at the Tanner Lectures in Utah in a talk entitled *On Beauty and Being Just,* Scarry wove into her message an insightful observation about the *process of receiving* prompting various forms of replication of beauty. She put forth the notion that a beautiful creation can cause the observer to experience a *radical decentering*. Beauty, she noted, whether in gods, gardens, persons, or poems, greets the observer and adrenalizes, which continues the creative experience—the realm of sensation. “Beauty, as art, is a call,” she stated. “Beauty is sacred, unprecedented and can be lifesaving. A beautiful work can lift one up to new ground.” (p. 17) Scarry leads us to see how “the perceiver, the beholder, gathers power and thus can become the pursuer of justice, armed with the peace that beauty and symmetry bring” (p. 17). Scarry inspires the viewer to become an activist, having been somehow changed. I am anticipating that viewers, however imperceptibly, experience a change in attitude, after having seen the pieces that I present.

Radio. Reports by Joseph Shapiro (1994) on National Public Radio are awareness promoting stories. He shares current sagas of people who are health challenged, who have disabilities, who are veterans, who are aging, those who have children and family issues. I attended his lecture at the University of Dayton’s Diversity Lecture Series in 2007. His presentation was on “The Overlooked Civil Rights Movement: How Heroes of the Disability Movement are Improving Life for All of Us.” He wrote *NO PITY: People with Disabilities Forging a New Civil Rights Movement* (1994), in which he positions people with disabilities with dignity and describes individuals and their stories of struggle for civil rights. His reporting is researched and accurate, and depicts individuals as people with whom we can all relate. The most poignant is the voice from which his stories are told: by the people themselves. He calls advocates who have disabilities “heroes.” I appreciate his viewpoint. Because public awareness is most effective from the source. Some heroes of the local movement helped me put together this exhibit. Latisha Martin is local chapter vice president of People First, a self-advocacy agency. She contributed to planning the exhibit, and consented to an interview. Claude Martin (no relation to Latisha) is one of our local heroes. His name is the title of a lawsuit filed against Ohio for keeping people with developmental disabilities in nursing homes and institutions, the Martin Lawsuit. As a result of this suit, the State of Ohio provided community homes for thousands of individuals who lived in institutions and nursing homes. Claude and his wife live in one of our homes. Both had lived in small institutional settings. He was a trustee on the housing corporation board for six years and was a great resource regarding accessibility, and he is a strong advocate for people with disabilities.

I met Greg Smith in 1999 around the time he was broadcasting his radio show, *On a Roll* (http://www.pbs.org/independentlens/onaroll/qa.html). Smith started *On A Roll* as a local AM radio program in Phoenix, AZ. His radio shows and his autobiographical movie capture contemporary challenges of people with disabilities. The call-in show offers people of all abilities to discuss the issues surrounding a base topic for the hour. Greg Smith also starred as himself in a documentary film about his life, also called “On a Roll.” I plan to use clips from the film to enhance my exhibit with motion, sound, and stories.

Film. Film is a powerful medium for educating viewers about another’s experiences. One of the best examples of film production companies is one in which films are created by and for people with developmental disabilities. The Sprout Film Festival is an outgrowth of a film company that has been producing films since 2003. From the creators comes a quote about the power of film:

> There may not be anything in the world more influential than the medium of film. Weaving socially responsible information into pure entertainment might be the quickest way to reach the masses to make a positive impact on relevant social issues. The Sprout Film Festival strives to create a unique

> experience that has the ability to educate, touch hearts, inspire ideas, and connect audiences. (DeSalvo, 2011, p. 1)

The creators of Sprout Films contend that "People with developmental disabilities as subjects and performers remain marginalized in the media" (http://www.gosprout.org/film/sff2011/general.html). This New York City based creative film production studio works from the philosophy that films present accurate portrayals of people with developmental disabilities, and in doing such, will break down barriers and stereotypes. I became aware of the company at a film viewing during a conference recently. The film was about a man who has moderate mental retardation and can live with drop-in supports to his New York apartment. His uncle provided oversight and financial support until becoming too elderly. The tenants of the apartment building where the individual lived pooled their own funds to form a trust to provide paid support. This heartwarming true story would inspire any viewer.

Lest We Forget is a film produced in 2007 by Partners in Community Living, a local public relations agency. This film is about the lives of people with developmental disabilities in Ohio and conveys their parents' reflections on the profound life experience. I interviewed Judy Leasure, writer and originator of the film, about her experience in making the award-winning film, which was entitled *Lest We Forget* "because the story had to be told," Leasure said. The film portrays life in state institutions for the mentally retarded and the stories of families of members who were placed in an institution "for life," but were subsequently discharged during the deinstitutionalization era. The emotionally moving documentary is a series of narration with pictures and interviews of participants. Leasure said that the process was "a remarkable experience, one that unfolded as one perspective led to another" (personal communication, July 21, 2010). Because I am in Ohio where the movement is documented, I watched the film with a variety of audiences. Although the attendees were there to view the film because of some connection to the topic, hearing and seeing the stories that were often uncomfortable seemed to evoke such empathy for individuals and family that many viewers were left in tears. Leasure stated, “Art is a non-threatening way to bridge a gap. It is nonverbal, and *everybody speaks art*!” Her film and life’s work of improving public images of people with disabilities are an inspiration.

Films have the potential to evoke emotions and prompt sensitivity. *Lest We Forget* and the films produced by Sprout are examples of films made by advocates and people with disabilities—films that provide information from the source. Granted, in most circumstances, the viewer elects to access and watch this form of media; however, an increased availability and promotion of good films about people with developmental disabilities will further make information available. This information provides truth and could serve to dispel myths.

Photography and Photovoice. Photography, as a medium, has played a significant part in public awareness of conditions in the institutions. The public has occasionally been treated to glimpses inside state institutions in newspaper or magazine articles published by professional photographers. Margaret Bourke-White (Trent,1994) was one of the first professional photographers to expose the public to pictures of institutional life. Her close-up portraits of “patients” working at important jobs at an institution and socializing in their Sunday best were intended to show industriousness as therapy. In the photos from 1940, patients at Letchworth Village, New York, were shown smiling as they worked in the kitchen or wove rugs, leaving the viewer to envision an idyllic life. However, a keen eye can tell that the images seem posed for the camera.

Despite the images, Letchworth was the first institution to have an entirely inclusive community, with its own farmlands, waste disposal, power-plant, and water supply. As a result of its progressive ideas for the care of the mentally disabled, it was also one of the first institutions for mental retardation in the world to establish a research department. Tragically, some of the research included experimentation on “patients.” Koprowski, the developer of the polio vaccine, revealed that he had become the first physician in history to test a polio vaccine on human beings at Letchworth. George A. Jervis won international recognition for his studies of phenylketonuria (PKU, a form of mental retardation) conducted at Letchworth Village (Trent, 1994).

In my exhibit, I showed photographs from Blat and Kaplan (1974), as they pictorially described their observations of conditions in institutions in their widely published book *Christmas in Purgatory,* which exposed a tragic reality:

> We were amazed by the overcrowding of wards, gross neglect of the older buildings, excessive use of locks on the many heavy doors and by the enormity of buildings and number of patients assigned to the dormitories.… We observed gaping holes in the ceiling of the main kitchen. In toilets, one sees urinals ripped out and toilets backed up. Beds are so arranged on some wards that it is impossible to cross the room without climbing over some beds. Beds are without sheets or pillows, and we have seen some beds so stretched by bodies that they are scraping the floor. (p. ii)

The following pictures are from *Christmas in Purgatory* (1974), and were viewed as a part of the changing photos in the digital picture viewers in my exhibit:

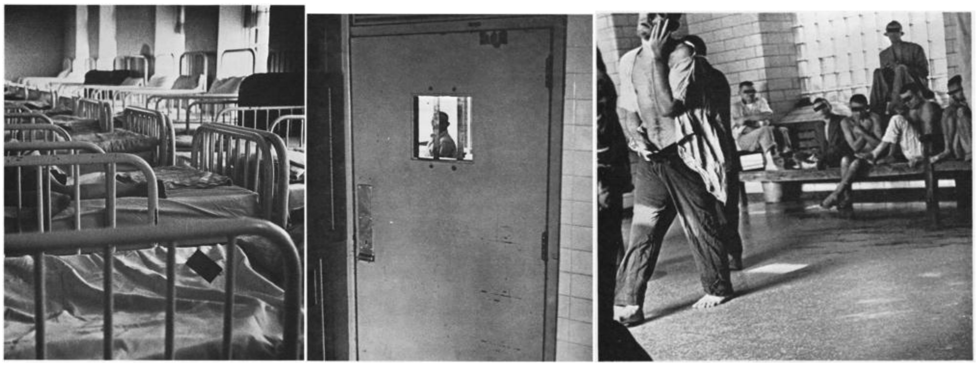


*Figure 2.*2 Inside a state institution

Photography is a silent—yet effective—medium to convey messages of human concern. Margaret Bourke-White, the Life Magazine photographer, was credited with showing the public how residents of a state institution in New York were industriously working during their days of institutionalization. But she also exposed many conditions of society through her profound photographs.

Bourke-White is celebrated as the first woman to enter the profession of photojournalism, as photographer at *Forbes* and *Life* Magazines. She boldly showed, in pictures, many sides of the Industrial Age. Carl Mydans of *Life Magazine* said:

> Margaret Bourke-White's social awareness was clear and obvious. All the editors at the magazine were aware of her commitment to social causes. She joined with other artists to form the American Artists' Congress that advocated state and public support for the arts and fought discrimination. (Cox, 2003)

Other photographers, over the years, have subsequently revealed life beyond the gates of institutions. In 1941, Arnold Genthe published photographs of Letchworth Village that showed more of reality: workers dressed like peasants serving the very institution that was to provide them with care (Trent, 1994). In 1948, a third photographer's photographs were published in the *New York Daily PM* and reproduced in Albert Deutch's *Shame of the States* (Trent, 1994). Irving Haberman reflected life inside the institution’s gates. “His photographs were an expose of the wretched conditions at Letchworth Village. Naked residents, unkempt and dirty, huddled in sterile dayrooms. Haberman’s patients were helpless quasi-human beings, the victims of what Deutsch called ‘euthanasia through neglect’” (Trent, 1994, p. 126).

I recently attended a conference at the Ohio State University, which has a disability studies department. It was called “Re-imagining Disability.” One session was on Photovoice, which “relies on giving research participants cameras to document their own lives” (Wang, 1999, p.185). A researcher who created a film autobiography of her life with bipolar syndrome presented her experience of making the film. She commented on how the experience enriched her life, made her feel able to face the public and has connected her with other individuals with the same syndrome.

Television. When television became a common household feature, people saw images and learned things that they may not have sought out. Geraldo Rivera’s television reporting on Willowbrook, the Staten Island State Institution, was sensational, but he did not need to further dramatize his report. The images and stories were shocking to the reporter and the public. Broadcasting the series prompted legislation that resulted in a movement to deinstitutionalize thousands of individuals, sending them back to their home counties in the state of New York.

Although a few *positive* representations of people with developmental disabilities in the media have made an entrance, such as the character who has a developmental disability in the television situation comedy *Life Goes On*. Chris Burke, an actor who has Down’s syndrome, played the part of Corky. Examples such as this are few and far between.

Posters and information distribution. Posters and other awareness materials, such as billboards and table tents, also serve to remind the public about disabilities. Public Images Network (PIN) is a source for posters and print media that has been useful in my work. PIN conducts an annual publication of posters and materials with themes of positive awareness during Developmental Disabilities Awareness Month in March. Themes of annual campaigns are positive in tone, not intended to agitate, but to invite acceptance, for example, “In the Heart of Each Community, Everyone Belongs,” the campaign which had posters, mugs with disappearing ink, and chocolate hearts; and “Allow Abilities to Bloom,” which included posters, T-shirts, and wildflower seed packets. Last year, the theme was “Just Like You!” Materials are sold nationally for a month-long media blitz, in which agencies can hang posters, produce billboards, issue a press kit, and hold events (the chocolates and seed packets were perfect for table settings at legislative awareness breakfasts).

When I was president of the Ohio Public Images Board, I contributed to the creation of many of the campaigns for awareness during March—Developmental Disabilities Awareness Month. The activity gave me an outlet for my creative side. I enjoyed thinking up the themes (always positive) and working with artists. Figures 2.3 to 2.8 are a few of examples of posters that the Public Images Network has used to promote positive images of people with developmental disabilities from different years of the annual campaign.

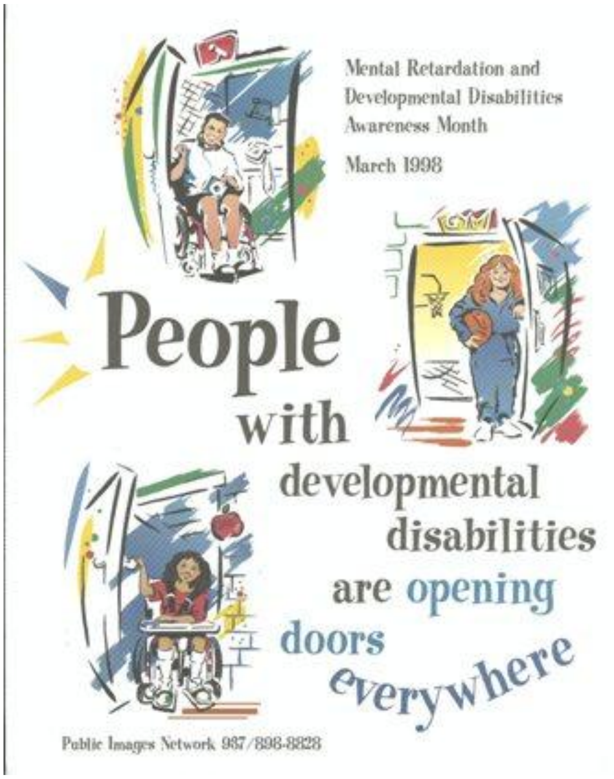


Figure 2.3 Public Images Network

Poster *Doors*

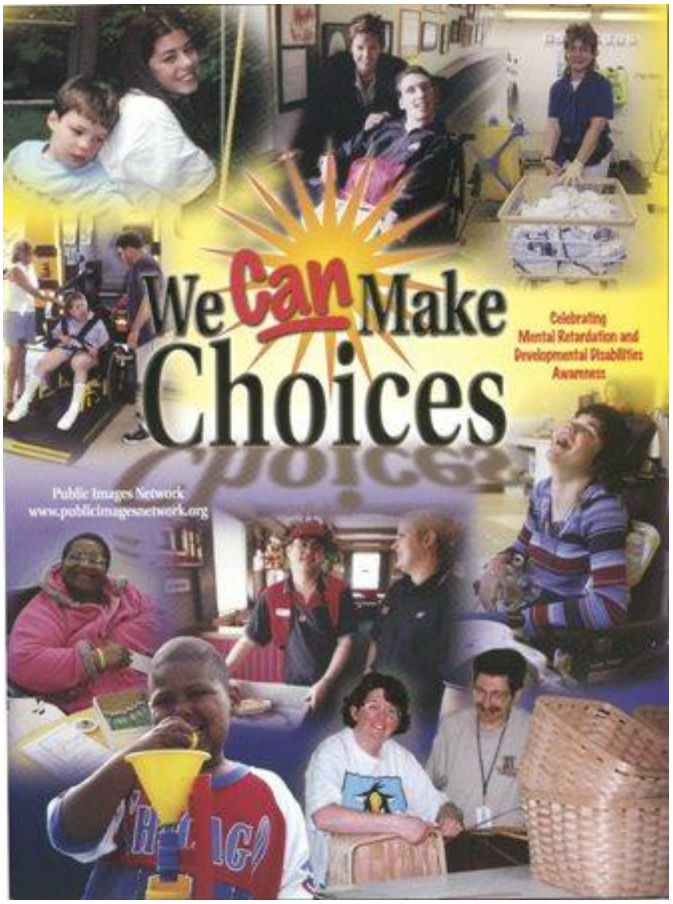


Figure 2.4 Public Images Network Poster *Choices*

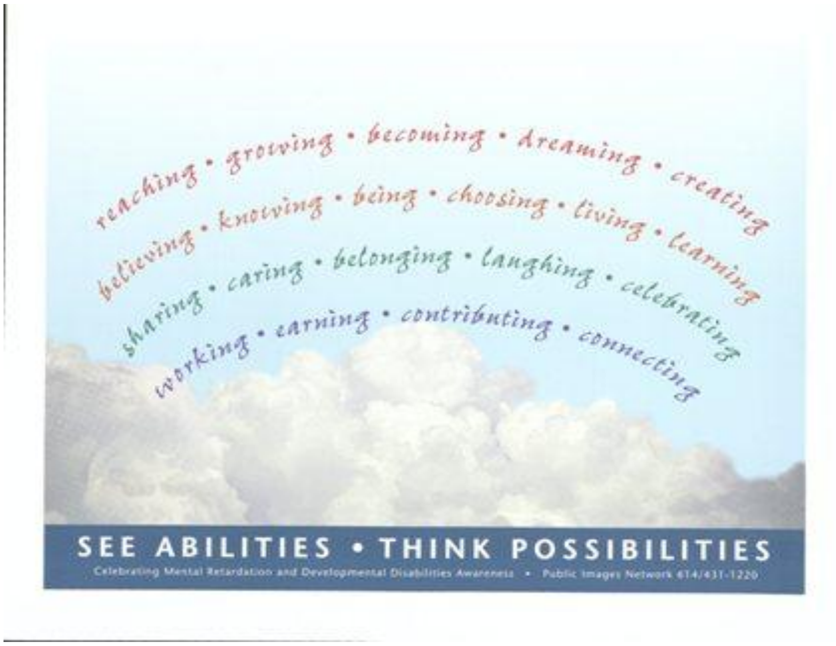


Figure 2.5 Public Images Network Poster**,** *Possibilities*

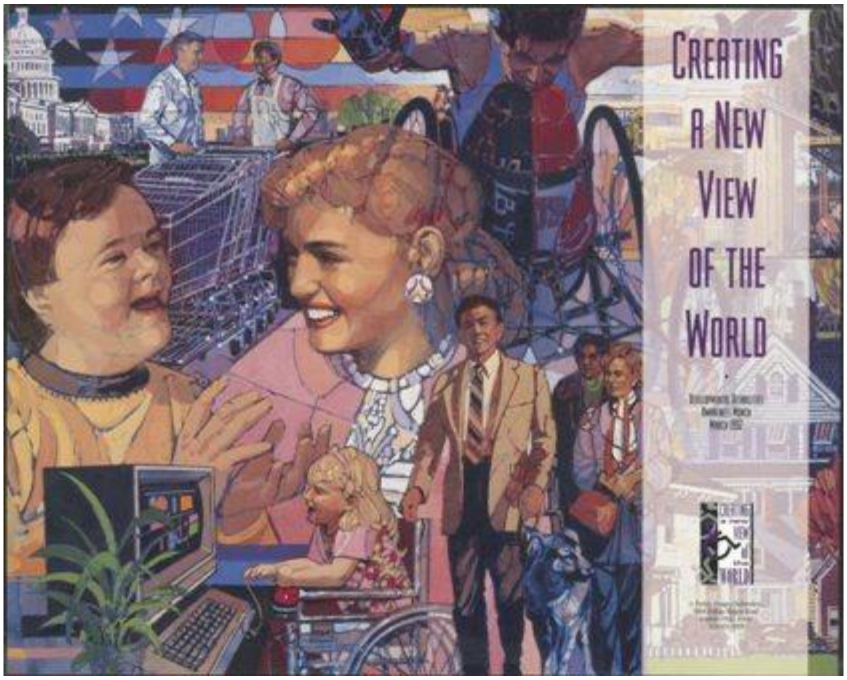
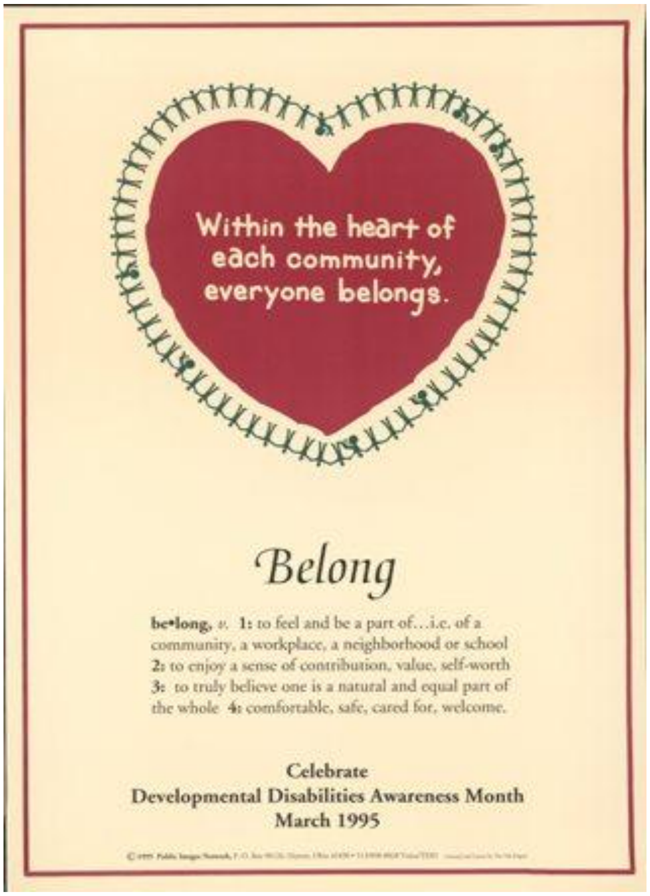


Figure 2.6 Public Images Network Poster, *New View*



be•long, *v.* **1:** to feel and be a part of…i.e. of a community, a workplace, a neighborhood or school **2:** to enjoy a sense of contribution, value, self-worth **3:** to truly believe one is a natural and equal part of the whole **4:** comfortable, safe, cared for, welcome.

Celebrate
Developmental Disabilities Awareness Month
March 1995

Figure 2.7 Public Images Network Poster, *Belong*

The "Belong" poster was very popular, and is a favorite. I worked with the artist to create handout materials for awareness events such as legislative lunches. Tasty handouts were the chocolates with the heart logo, easily placed at each place setting. But the most fun item was the mug with a heart on it; inside the heart was a message that only appeared when hot liquid was poured into it. The artist for this poster, Dan Wilkes, has a disability and uses his art to advocate for people with disabilities. He created three posters for the Public Images Network, and also distributes his own print material promoting the awareness of equal rights and inclusion. Dan also speaks at conferences and provides in-service training for agencies in the public and private sectors.

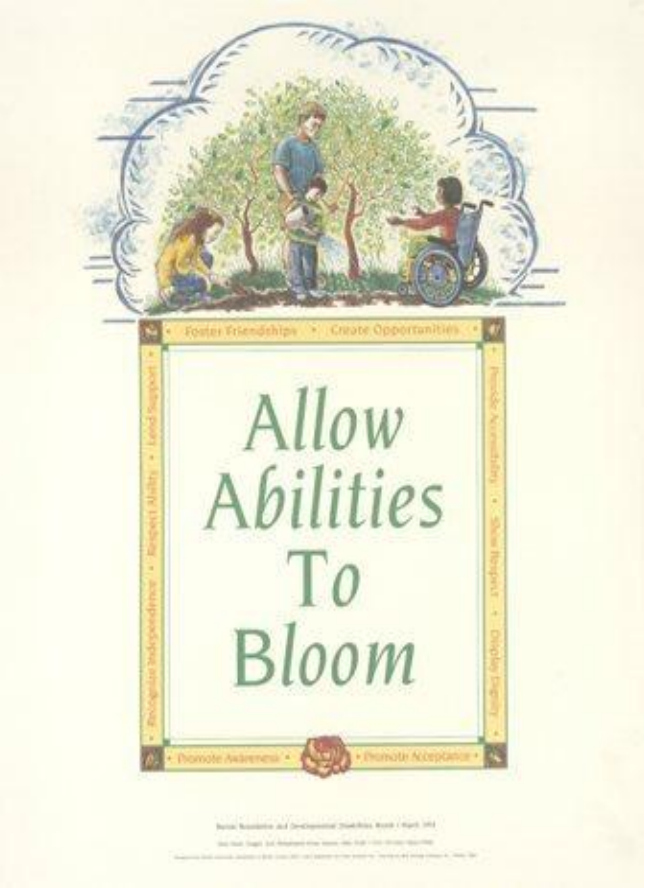


Figure 2.8 Public Images Network Poster, *Allow Abilities*

The poster in Figure 2.8 was distributed in the springtime, so we produced wildflower seed packets with a miniature of the poster printed on the front. An illustrator who I met at an illustration class, Mel MacArthur, created three graphic posters for Public Images Network. She shared that she was intrigued by the mission of the agency and is proud of her contribution.

Accessing a variety of arts media for awareness and social change purposes has great potential to influence attitudes. Intrigued by the utilization of art for social change, I chose arts based methodology for its ability to inform through creative means and its potential for stirring emotions and enlightening minds. Where resistance to assimilation occurs, I find myself stretching my mind in an attempt to understand. It is my mind-stretching activity that draws me to consider using the arts for awareness, as the arts have demonstrated potential to evoke such a reaction. Concurrently, I find great potential and merit in various means of arts based research. As an example of the power of a genre, Denzin (2003) quotes Giroux and Madison regarding the use of performance art for awareness: “Performance-based human disciplines can contribute to radical social change, to economic justice, to a cultural politics that extends critical race theory and the principals of a radical democracy to all aspects of society” (Giroux as cited in Denzin, 2003, p. 1). ”As pedagogical practices, performances make sites of oppression visible” (p. 14). ”A performance of possibilities gives a voice to those on the margin, moving them for the moment to the political center.” (Madison as cited in Denzin, 2003, p. 18).

Chapter III: Methodology - Arts Based Research

Choosing a methodology for dissertation work was both challenging and delightful. I chose arts based research for inquiry into the phenomenon about an ethnographic group, specifically people with developmental disabilities, and the community resistance or acceptance of this marginalized group. Using arts based research to look at this population, I find many possibilities: visual art exhibitions, drama, dance, poetry, and storytelling. Narrative also has a long history as an art used for research. I chose the use of visual arts in an installation form because of its uniquely nonverbal means of telling the story. As Bagley & Cancienne (2001) state, "Somewhat less prevalent are those researchers who have experimented with non-linguistic art forms, but they do include collage, music, photography and dance to tell their educational stories" (p. 56).

Arts based research can utilize the arts to mine data, which can be in the form of factual information, subjective experiences (interpretation), feelings, and effects in the form of representation. Arts based inquiry can be a primary mode of research, or it can be part of a mixed-method approach, in conjunction with other modes of inquiry. For example, a researcher may document an arts informed life history, or conduct an ethnographic research project using the arts as a mode of information gathering, as well as interviewing and fact-checking. "The central purposes of arts-informed research are to enhance understanding of the human condition through alternative (to conventional) processes and representational forms of inquiry, and to reach multiple audiences by making scholarship more accessible" (Knowles & Cole, 2008, p. 59).

Arts based research is moving more into the mainstream. This is evidenced by the publication of handbooks, articles, and teacher and counselor education programs and curricula. Among the many reasons this creative type of inquiry may appeal to professionals who work with people could be that the researcher observes the complex process of *making meaning* through expression by the participant(s). For example, Hunter, Lusardi, Zucker, Jacelon, and Chandler (as cited in Leavy, 2009) describe the use of the creative arts in addressing inquiries in health care as an *iterative* process. As opposed to a linear approach, *patterns* emerge through labelling, identifying, and classifying information. "Hunter and colleagues argue that visual and other arts based methods make this process explicit, allowing qualitative researchers to better accomplish what they already do—arts based practices draw out the meaning-making process and push it to the forefront" (Leavy, 2009, p. 11).

However, bringing the arts into research about people with disabilities is an emerging area of method for inquiry. In 2000, Crutchfield and Epstein noted a confluence between disability, art and culture, now beginning to occur: "Until recently, we have had few intellectual spaces in which activists, scholars and artists could investigate the breadth and scope of disabled experience and representation" (p. 3). Still expanding as a method of research, the arts based approach is ideally positioned for the work of inquiry with a human condition.

A research method must be chosen, of course, as the most effective tool for the purpose of researching one's question or issue. My quest was to find a way to create awareness of people with disabilities as individuals who are entitled to live their lives to the fullest potential, and to participate in the community with all of the rights and privileges to which we are each entitled. The evocative characteristic of using the arts was ideal. I have attempted, through verbal means, to help the public understand that people with disabilities living in their neighborhood would be a positive experience. Because the act of showcasing actual people is insensitive and a violation of privacy, I chose to install an exhibit that displayed the history of treatment and evolution of services. The exhibit also displayed landmarks in the effort to improve people with disabilities' quality of life, and challenges that remain. In addition to my own multimedia presentation, the exhibition included art from people with disabilities. True to critical ethnography's approaches, research was done through the process of discovery while creating the exhibit, talking with viewers, interviewing a selected group (of five), and recording reflections in extensive field notes.

Two elements that are critical in arts based research itself are: 1) choice of medium, and 2) the art experience of the researcher. Knowles & Cole (2008) comment on art form:

> The relationship between and among research purposes related to knowledge advancement and research communication, art form, and the artist-researcher's grounding in and developing expertise/competence with the chosen art form is key. Indeed, form is the main defining element of arts-informed research. (p. 62)

As a researcher, one needs to be articulate in a methodology in order to use the approach as a tool and to see, feel, and know its power to move the viewer from one vantage point to a new vantage point. I am an artist, and although I do not produce art for a living, art is a passion and means of expression for me. I found the experience to be engrossing, challenging, and both energizing and, occasionally, anxiety producing. Fascinated with the production of a multimedia installation, which required research on the ethnographic group of focus, I experienced engagement in the various media of visual art, photography, digital production, and design composition, as well as learned more about the issues of people with disabilities living in a community.

The Exhibit

My conception for an educational, evocative display was to follow a timeline in history that marks the progress of civil rights for people with disabilities. In segments, the exhibit moved from depictions of how people with developmental disabilities were treated in dark and dingy asylums. An institutional ward was modelled—showing metal frame bed, wood bench, bars on the window, and the old locker in which a person stored all of his/her personal belongings. Digital picture viewers mounted on the model of a state institute revealed the scenes inside. I played the voices of parents who had placed their child in institutions. They shared their emotions of a mixture of loss and guilt. Doctors, at that time, had told parents that the institution was the best place for their child. Credit is due to parent and advocates who had the courage to take the needed access to education, opportunities to work, and improved residential services to the courts.

Materials were created, borrowed, made of found objects, and minor purchases. Costs of art medium and surfaces were mine to absorb; however, tables, easels, and some posters were available at no cost through the Montgomery County. In gathering examples and means of arts based research, I had access to materials that fall into the realm of art that creates awareness. Readily available were: print material in the form of photographs, posters, and newspapers, film clips, radio clips, and pictures done by artists with disabilities. The technological devices both owned and borrowed included digital picture viewers, laptop computer, and digital tape players. Security guards assured that no theft occurred of such devices.

In the exhibit, photos of individuals engaged in social and recreational activities in the 1960's and pictures of the group homes of the 1970's were shown in a second digital picture viewer on the other side of the model of the state institute. News articles announced neighborhood resistance. The clippings showed the harsh words that have been said, and point out the barriers to accessibility, zoning laws about public hearings, and other examples of the NIMBY (Not In My Back Yard) that we have witnessed. Pictures of group homes showed the early models, which were large two-story homes with eight to twelve individuals living with houseparents. More pictures were shown on digital viewers about lawsuits regarding mistreatment; these legal actions required change that resulted in moves to the community for most formerly institutionalized individuals. Photos of people with disabilities in the different settings were printed onto the translucent medium of white silk. They were then placed into a flexible frame that appeared to be an enlarged filmstrip. The "filmstrip" was aligned to show the progression of settings, from institution to group home, and finally to the houses we now develop in typical neighborhoods. Also, attached to the top of the filmstrip were colorful index cards on which were handwritten notable events. The cards were mounted at a 45-degree angle, appearing to be notes from a sociological study. As the viewer moved through the tabletop portion of the exhibit, they saw pictures and words and heard the stories. At the end of the exhibit, snapshots of the supported living homes of today pictured people enjoying their homes.

The multicolored, multimedia display drew many viewers, who had mixed reactions. At the end of the exhibit was an art pad equipped with colored markers, inviting comments. Among the kudos for the social services work for people with disabilities, I received thoughtful notations. I was thrilled to have so many responses of a deeply felt nature. The arts evoke feelings, even though the messages are not always positive. Use of the arts to increase social awareness, as a means to give voice to the disenfranchised can help to create understanding and compassion.

Depicting the ugly side of society can be uncomfortable, but that discomfort is often what moves people toward a change of heart. In the work of Martha Rosler (1991), who produces public art that is often uncomfortable, it is not meant to be attractive. Instead, it is meant to evoke the disconcerting position of its subject. Agitation can serve to shift one out of a sense of rosy well-being; this is the intent of art that provokes. The question is posed: How can one shift into new awareness without being, in some way, disturbed? So, I displayed samples of the discriminatory language that I have recently heard. As evidenced in previous chapters, the challenges in neighborhoods remain. Although zoning codes allow housing development on a smaller scale without permits (four people in a single-family house), I still hear resistance from neighbors. I am sometimes put in the position of meeting with unhappy homeowners, and I then put forth an effort to listen and understand their concerns. I verbally attempt to allay their fears, but NIMBY attitudes still emerge, sometimes expressed in intolerant language.

The viewers were the participants in this research. Viewers came from many different viewpoints. They included: professionals who work in the county building, people coming in to pay their water bills, the security guard, the chief inspector for buildings and regulations in the county, clerical workers, federal subsidy recipients, staff who provide services to people with developmental disabilities, people with developmental disabilities, and parents of children with disabilities and children. People who may or may not have an immediate interest in the topic viewed the exhibit. The space was a public lobby of the Montgomery County, Ohio, building that houses local government offices. The space was right inside an entry door. Tall windows allowed for natural lighting. The Montgomery County Administration Building is open to the public for dealing with such matters as: building permits, property tax, licenses, entitlements (publicly funded benefits), community and economic development, public hearings and information sessions, and county government. Thus, a broad range of the public flow through the main lobby during weekdays.

As installation artist, I considered both message and diplomacy because the art was displayed in the government building. I became a sort of mediator between the viewer, subject viewed because I had certain control of the subject viewed. This didactic is

displayed in Figure 3.1.

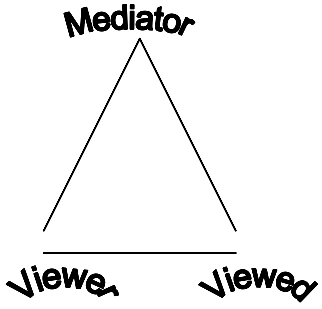


Figure 3.1 Researcher’s depiction of the artist as mediator

The exhibit was created to stand alone, with or without accompaniment by the artist/researcher. However, I spent at least two hours per day at the exhibit, at varying times as set on a flyer which announced my schedule of presence at the site. The general public meandered by, and so did county officials. Leaders in government, some of whom actually decide on the funding for my nonprofit housing corporation, viewed the exhibit including: County Commissioners, County Administrator, Community and Economic Development Directors, Planners and Buildings and Regulations Directors. These officials would want the public, the taxpayers, to have a good impression of our (collective) housing efforts. They saw successes celebrated, in this exhibit, along with the ugly history. The key administrators are aware of and share in the struggles that we have had in certain neighborhoods within certain jurisdictions. All things considered, diplomacy was a factor in how I presented this artful display.

When present at the installation, I was sensitive to the emotions that viewers seemed to be experiencing. Observing faces that were somber when viewing the institutional portion of the installation, I remained available but gave people space. As viewers' eyes rose to the index cards that noted progress, and the attached filmstrip of 8" x 10" photos that went from black and white to color, I remained available for small conversations. This openness, on my part, seemed to allow the participants to feel more comfortable in sharing comments. I encouraged them to record remarks on the pad of paper furnished with colorful markers.

Having spent as much time as was feasible, however, I did not have the opportunity to hear all of the spoken responses to the pictures, stories, visuals, and audio presented in the installation. But, what I did observe provides a rich collection of responses. Along with kudos for the effort, written comments included shock, sympathy, blessings, and words of encouragement (e.g., “keep moving forward” and “an ongoing journey”).

Figure 3.2 Viewers at the exhibit (above) *Figure 3.3* Model of ward at exhibit (below)

Chapter IV: Results of the Research

> The rethinking of ethnography is primarily about speaking and listening, instead of observing ... [shifting] emphasis from space to time, from sight and vision to sound and voice, from text to performance, from authority to vulnerability. (Conquergood, 1991, p. 180)

Introduction

The results of this arts based research study are presented in varied form. I wanted to find out if the exhibit influenced viewers' attitudes regarding people with developmental disabilities. So, I kept a record of the process of developing the project in field notes, took pictures of the product (exhibition), and recorded written and verbal comments during the exhibition in print and photos, and questions and answers from interviews of a selection of viewers. In this chapter on results, I will show a relevant sample of the data that was recorded through these pluralistic means. In order to clarify the use of each method of collecting data from this study, a description of each is offered below.

Pictures of the exhibit. The color photos reveal the open space and bright lighting in the public hall where the exhibit was erected. There was an apparent linear flow to the exhibit, as most viewers were initially drawn to the small grouping of furniture on the left end; then they naturally moved to the table-top model of an institution and photographs to the right, and then toward the pictures of residents in the current model, typical homes. Photos of the installation show the segments that made up the whole.

Field notes. Field notes were written from the beginning of the project's conception. I incorporated input from both people in the ethnographic group, and staff who work with people with developmental disabilities. I wrote my own thoughts on the process of creating the installation, the comments made during and after the exhibit, and my personal reflection on the experience. My notes are random, subjective, and reflective, at once, as they were written from having been immersed in a process. My field notes include landmarks in the history of residential treatment of people with developmental disabilities, the resources for my research, and a flood of thoughts that occurred to me, from the development to the completion of the interviews.

Written and spoken comments. Many viewers verbally commented on the exhibit in my presence, both during and after the installation was dismantled. When I was present at the exhibit, I engaged in small conversations, then I recorded these in my field notes, and I also invited people to write on a pad of paper, beside which were inviting colored markers. A number of viewers took the opportunity to record their reactions to both the subject and the display. Responses were surprisingly deep and filled with emotion and personal thoughts about society's treatment of people with developmental disabilities, both in the past and today.

Interviews. Selected viewers were then interviewed about their experience of seeing the exhibition and their thoughtful reflections. I wanted to see what resonated with them, and to delve more deeply into their impression. For the interviews, I had a template of questions, but I conducted the interviews in an open rather than structured style. The focus was intentionally on the exhibit, because I was researching the effect on the viewer/participant. However, dialogue moved along in a natural way, resembling a discussion with focus. Holloway (2006) recommends that, during an interview, the researcher should be aware of how one makes meaning: "through filter; go in with an openness and allow articulation of layers of talk so that meaning, knowledge & perspective came out of talking" (Holloway, 2006).

The Exhibit as Experienced

Displayed in the Montgomery County Building main lobby for three weeks, from March 14 to April 1, 2011, the installation was viewed by the general public from all walks of life, as well as county employees. It began with a simple model of a ward in a state institution, composed of symbolic objects: a grouping of representative furniture that could have been a part of an institutional ward. A descriptive passage, below, brings the experience to the reader. Photographs of the installation are on the following pages.

Let us walk through the installation, as if you were there, and out of curiosity, have become a viewer/participant.

After driving in circles to find a parking spot, and taking the elevator to the main lobby of the Montgomery County Building, you feel warmth as the sunlit walkway provides a welcoming transition from the cool concrete parking garage. Entering the expansive lobby, you note the hubbub of activity everywhere, as people buzz by on their missions to take care of whatever business they came to do that day. Across the lobby, in front of the tall windows, you see some odd-looking furniture beside long, skirted tables topped with a curving and colorful display. You wonder what this is about. Migrating toward the attraction, you see three stark pieces arranged in a U-shape, and you start to feel you are in a strange room. You focus on each item carefully positioned in a grouping. First, you see a pitted black metal bed frame—the kind you had at summer camp. An old cotton flannel sheet is loosely pulled up to the flat pillow. A handwritten tag taped to the old, arching headboard contains the words “Ward of a State Institution.” You think, *How bleak!* Your gaze now falls on each piece of furniture placed on a stone-like floor. The set of three old army-green lockers has another tag: “Residents had to store all they had in a locker.” A recollection of the sound of locker doors comes to you from high school days, and you cannot resist the urge: you click the latch up with your fingers and the door opens with a creaky sound; the hollow metal chamber smells of dust and rust. Beyond is a window frame appearing to have bars on the outside. “Looks like a prison,” you mutter. The conceptual parallel of a state institution for people with mental disabilities and a prison darkens your mind, and the feeling of discomfort gives you pause. You wonder about the experience of having an entire life in an institution, just for having mental disabilities. With a sigh, you think, *Perhaps the collage of colorful pieces on the tables will soothe these disconcerting thoughts, or, at least, add information to make meaning of these stark symbols.*

You are drawn to the artful display on the table by the sound of an acoustic guitar. The male singer’s voice coming from the speaker of a computer is pleasant, but the words catch your attention: “For the crime of being different; for the crime of being slow, you have sentenced me to go, to live in far off buildings, with others of my kind…” The song is sad, but brings forth the story the images were intended to tell. You sense there is more to the story. The bright sunlight streaming through tall windows behind the installation illuminates pictures that promise to explain further the connection between object, sound, and words. Your eyes are now examining photographs in a filmstrip-like frame that snakes along the top of a model of a brick building. You visually take in the old architectural style and see the block letters above the large doors that say “State Institute for Idiots and Imbeciles.” These appellations take you back, as these are harsh labels, generally known to be derogatory in today’s culture. *Like the old*

Dayton State Hospital on the hill, you think as you recall the foreboding look of the huge buildings up on Wayne Avenue that were where people were sent when deemed to be insane. The images of children in the pictures in the filmstrip and changing pictures in a digital picture viewer show people who lived inside the fortress. Barely clothed in hospital gowns, thin figures sit crouched on long wooden benches; some are standing barefooted on concrete floors.

It looks crowded and dirty, and lacks any signs of comfortable furniture. Thoughts flood your mind of how it used to be—how in the 1950's, if a child was not "normal," not "right," they were likely to be put in state institutions. You wonder, *What happened to all of those people? Where do people with disabilities live now? How could society have allowed such poor conditions to be habitable, especially for people with so many needs?"*

Your eyes are attracted to a row of angled, colorful index cards, again with handwritten tidbits of timely events, and you read a few. Cards in green, salmon, yellow, and deep pink sculpting the top of the "filmstrip" by their angular pose are written as if to be field notes from research. The information helps you to "connect the dots" about the intention of this display. The theme becomes clearer as you read about historical moments in housing people with disabilities. You are reminded of watching Geraldo Rivera's dramatic exposes of conditions in institutions on television, and are shocked to read about how sterilization and lobotomies were conducted up until 1970 on people who were then called "feebleminded." Reading that the Fair Housing Act was amended to include people with disabilities as recently as 1988 astounds you. You read in a newspaper clipping tacked to a trifold display board about neighbors upset by a group home locating near them. You wonder how you would react to a group of people with disabilities living in the house next door to you. As you realize that one’s home is fundamental, and that this issue may be hard to resolve for homeowners as well as for the individuals with disabilities who share a house in a neighborhood of families, you feel the weight of complexity of this societal issue.

Looking now at slide after slide in another picture viewer, you note the joy in the face of a young man with Down’s syndrome who is working on a computer. You think about how full a life can be, if one is offered many opportunities. *Perhaps*, you think, *that young man is even earning a living!* You are reminded of a boy in church, the one who likes to greet everyone with a handshake and a “Hi,” and you consider his future. *Will he live in a house like these modern homes shown in the photographs, with other people with disabilities, or stay with his parents?*

At the far end, you note a square table with a note inviting comments. A box of Crayola markers in many colors invite you to add your own comment to the big newsprint paper already splotched with writing. You see that many people have written in random directions on the pad, and you choose a bold color to comment. Thinking of the feelings you had as you viewed the old ward, heard the voices describing conditions and experiences, and read the historical reminders, you are moved to share some of your reflections.

This fictitious account of a viewer of the real installation illustrates how art-inspired installation evokes visceral responses and thoughts. Cole (2004) expanded on Sardello’s “aesthetic contemplation” (1976): “Research becomes a site of aesthetic contemplation when feelings, intellect, and perception are given space to come together to make meaning" (p. 312). The viewer experienced the elements of the installation, given their various sensational qualities, and then internalized and came to understand the point. The viewer, now participant, contributed to the research by making her own comments on her reaction, in order to continue the story.

Photographs of the exhibit on the following pages show the setting, lighting, and large and small-scale elements.

Figure 4.1 Model of bed

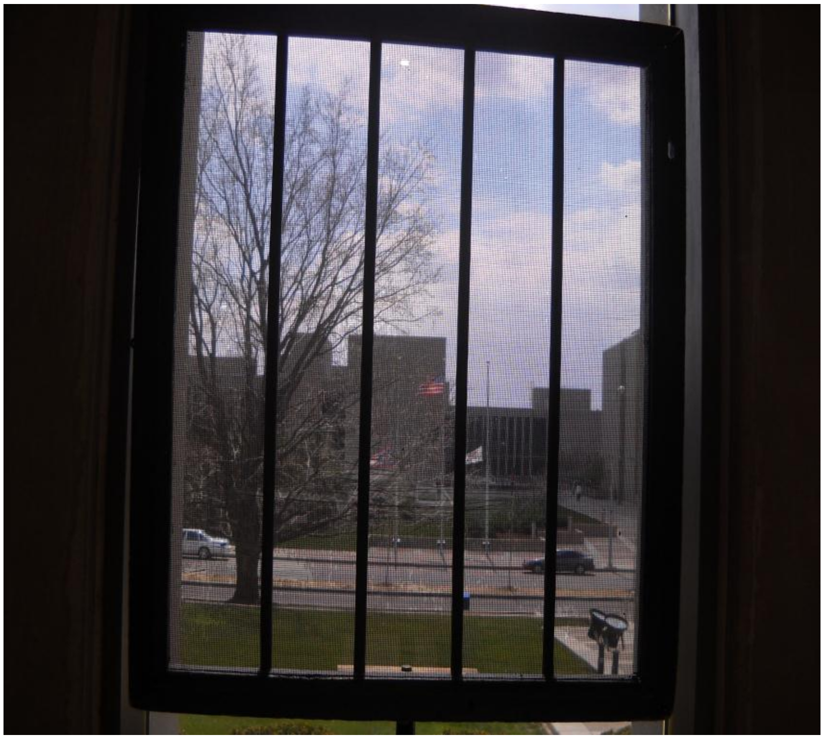
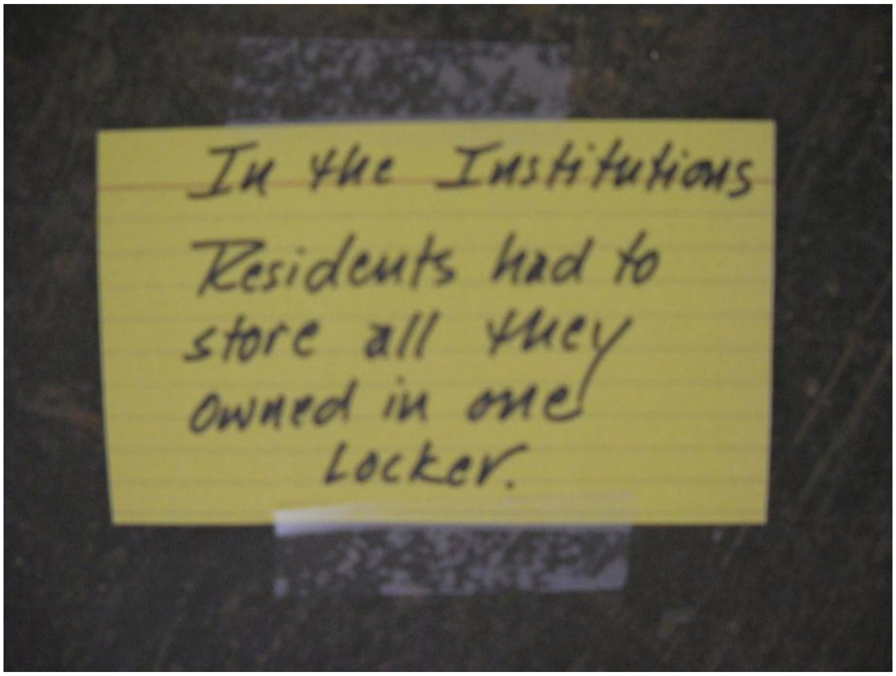


*Figure 4.*2 Bars on window

Figure 4.3 Old lockers



In the Institutions
Residents had to
store all they
owned in one
Locker.

Figure 4.4 Note card on locker

Figure 4.5 Model of a State Institute for Idiots and Imbeciles

Figure 4.6 Model of a State Institute for Idiots and Imbeciles

GROUP HOME TO OPEN

9.29.74
DDN

Neighbor Takes County to Court

By PETE FUSCO, Daily News Staff Writer

Robert Muzechuk bought a home in Centerville

Figure 4.7 Picture viewer showing newspaper articles and group homes

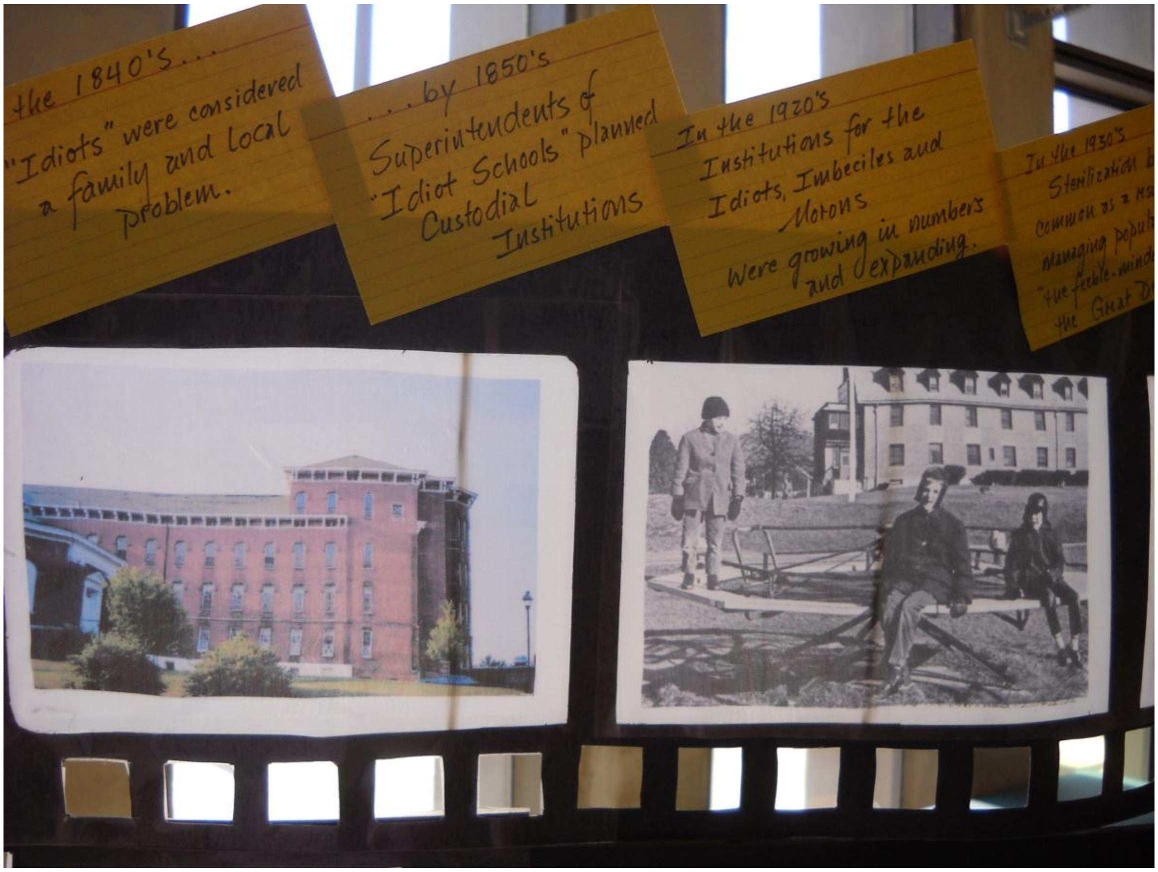


Figure 4.8 Notes on index cards above the filmstrip telling of historical treatment And marked events in the disability rights movement.

Figures 4.9 & 4.10 Snapshots of homes and people in supported living settings

Figures 4.11 & 4.12 Snapshots of homes and people in supported living settings

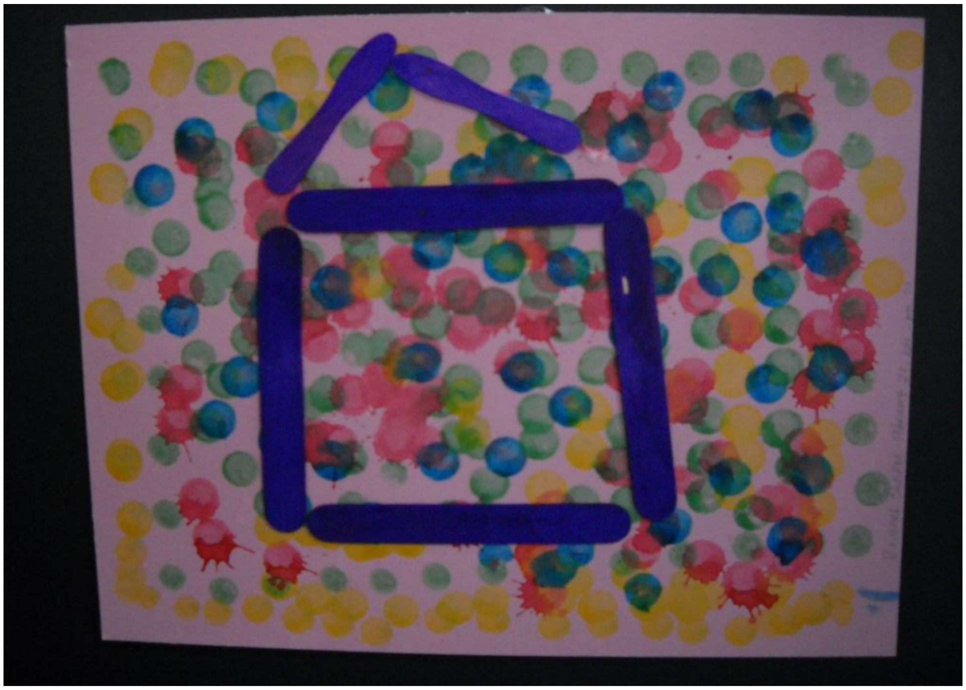


Figure 4.13 Art of “home” by people with Developmental Disabilities was donated by

We Care Arts Art Café

On the skirt of the table were the four posters from the Public Images Network's 2011 Developmental Disability Awareness Campaign, which was "Together, The Future is Brighter," "Together, We Inspire Possibilities," "Together, We Accomplish More," "Together, Everyone Wins." The positive messages imply an inclusive society, where people with disabilities are part of the community.

Field Notes

Recorded throughout the experience of developing the research, my field notes document the planning and the creation of the installation from the very beginning, as in: talking with people about ideas, getting their input, noting resources, gathering literature, and jotting ideas for materials for construction. Starting with the first notion that I shared with a colleague, I began to hear stories come forth, and I began to take notes. My book of notes contains a record of short conversation and descriptive narrative, with interpretive comments, woven into it. In journal mode, at times, this record of the process included my ideas from inception, to production, to writing up the research.

Field notes about project development. I began recording my interactions about this research project from its very inception. Once having decided on arts based research as methodology, I noted a number of inspiring examples of exhibits that create awareness in the viewer (field notes are in quotes followed by reflections, ideas, and plans for the project):

"The Simon Wiesenthal Museum of Tolerance in Los Angeles." The exhibits are a powerful stimulus to explore crucial themes such as the power of words and images, the pursuit of social justice, and the relationship between diversity and democracy. This museum creates an experience for the viewer by participation. When my cohort visited, we each took a small paper with a name on it, which was an actual name of someone who had been in the holocaust. I had a small child. I found out at the end that she was lost, probably exterminated in a gas chamber. I also remember that the day we visited was my birthday, and the timeline that was painted on the wall noted an event in 1954, the year of my birth, which sounded like an event that could take place today: "Thousands of illegal immigrants were deported to Mexico." The timeline idea remained with me, so I used index cards to show events in the history of people with developmental disabilities in my exhibit.

"Rosler—If You Lived Here." I gained inspiration from a book about the installations of Martha Rosler (1991), who uses art to create awareness of resistance to housing development in New York City. She has been concerned with gentrification and what the destruction of affordable housing does to the low-income individuals who live in targeted neighborhoods. Rosler exhibits in public spaces, even city halls, to communicate messages, which are sometimes uncomfortable to hear and see. This latter point makes what she wishes to say stand out. This impressed upon me not only the importance of art for social change as being attractive, but also the importance of a "shock" factor.

"Talked with Mark in supervisory meeting…he brainstormed quantitative methods; control groups where viewers took before and after surveys. Told him that this is a qualitative study…described arts based research." When I first mentioned the idea of an exhibit to my supervisor, Mark Gerhardstein, he knew that I wanted to conduct research for my PhD. Mark is the superintendent of the Montgomery County Board of

Developmental Disabilities. His wife, interestingly, is an art therapist. Mark liked my ideas, but arts based research was new to his already broad knowledge base. He knows, from experience throughout his career, that integration of people with disabilities into neighborhoods is fraught with challenges. He suggested before and after surveys and control groups—the methods used in quantitative studies. I explained that this was to be a qualitative study, which he seemed to understand and, perhaps, respect. He demonstrates that he knows the power of storytelling, as Mark appeals to officials and resistant neighbors at zoning hearings and presents stories about the people in need. He has a long history in this field that began while he was working at a state institution in the 1970's. I later interviewed him, and he took the opportunity to offer a history lesson from his memories, telling vivid stories. As a result of talking with Mark, I gained support and was offered the space in the Montgomery County building for the exhibit. Along with a strong endorsement, he offered contacts to assist me in the development of the project. (He did not, however, indicate that I could use on-the-job time for the work; it was to be done on my own time). As a result, I took time off to write and defend my proposal, to create the installation, to set it up, and be present at short intervals during the scheduled display.

Originally, I had had grandiose ideas of a walk-through exhibit, complete with rooms that depicted a ward in a state institution in the 1960's, much like those shown in the photographs from the publication *Christmas in Purgatory* (1974). "Rooms lit by bare bulbs…big windows with bars, no curtains…beds at one end, TV high in corner at the other." I wrote that I envisioned the viewer pushing a button to watch a video and to hear the voices, along with lots of graphic messages on walls and ceilings. This would be followed by a room in a crowded group home with neighbors' voices of resistance outside the windows. At the end of the exhibit, I envisioned a setup like the living room of a supported living home of today, with a couch, chairs, and coffee table. Paring down to the space was a necessary challenge, and I believe this activity was a catalyst to better concision. Concision is one of the criteria that Barone & Eisner (2012) cite for effective research using arts based methodology, and is defined as:

> the degree in which the work of art occupies the minimum amount of space and uses the least amount of verbiage necessary for it to serve its primary, heuristic purpose of enabling members of an audience to see social phenomena from a fresh perspective. (p. 149)

"Saw space today—Great Lighting!" When I first saw the space for the placement of the installation, I was so impressed with the lighting. Tall windows allowed light to fall on shiny terrazzo floors. I began to consider how to maximize its natural feature. "Windows face south—great light," I wrote, and I brainstormed ideas on how to make my vision for the exhibit happen in this very real place. I practiced dying silk, but when I was informed that I could not hang anything on the windows, I began printing photos onto silk I had found at a chain fabric store. I placed the 8" x 10" pictures in a black, flexible cardboard frame cut into strips along with peg holes to in order to mock a large filmstrip, as shown in Figure 4.14.

Figure 4.14 Flexible cardboard matting made to look like filmstrip

As the process moved along, my notes became lists of materials, ideas for resources, and conversations with colleagues and friends about the exhibit. I elaborate below the experiences that unfolded as I carried out the development of the installation.

"Find an old locker and bed frame." I had remembered that one resident I knew, Donald from Columbus State Institute, kept all of his things plus his map collection in his locker. Everyone in the institution had only a locker for all of his or her belongings. Sometimes these would be cleaned out when the resident was off the ward, or sometimes, personal items were stolen, so Donald carried as many of the maps as he could around the campus of Columbus State Institute all of the time.

On weekends and after work, I drove around to scrap yards, flea markets, and antique stores that were dusty and full of "good" junk. After seeing a play in a small theater one night—the play was called "The Boys Next Door," and was about a group home—I even sneaked around the sets, looking for bed frames. Days later, I spied a couple of sets of old lockers at First Street Recycling. After attempting to ask the workmen who spoke only Spanish if I could borrow a particular set of lockers for an art exhibit, the men working the yard told me to come back on Saturday so I could talk with the owner. The owner was a man with an expressively lined face, who said that he is glad to contribute to the arts, but a $50 payment now and refund of $30 later would allow me to be in possession of the lockers for a month. I shared with him the theme of my exhibit. And, after a moment staring at the floor, his mouth set in a partial smile, he recounted *his* experiences of working in deinstitutionalization. The mention of the era brought a memory back to him of two elderly sisters who had spent 50 years in an institution and were being returned to Darke County, Ohio, where he lived and worked in a nursing home. Tears came to my eyes on that Saturday at the junkyard as he told the story. He said he would never forget the people, and he hoped he could get to see my installation.

"Met Jackie at the Market—she shared story about her sister." Personal stories emerged from so many people that I spoke with about my plans, such as that which had come forth from the owner of First Street Recycling. We live in a time of self-disclosure, and as a culture, I believe we are all the richer for the sharing. After running into Jackie at the Farmer's Market, and discussing with her my exhibit ideas, I discovered, for the first time, that this long-known colleague of mine had a sister with severe disabilities. Her mother had placed her sister in Stillwater Center for a few months (prior to the old building's demise), but her sister developed bedsores and their mother was not satisfied with the level of care. Her sister died at a later time, while living at home. Jackie, who has worked in disabilities services for a long time, had learned to be sceptical about residential settings. Her own son has developmental disabilities and is living in an apartment with supportive services. Understandably, she is very particular with the agencies that provide direct care services for him. The experience of her sister, who had been poorly cared for in the institution, had left an indelible mark, forever placing her attention and concern for health and safety in the forefront.

“Audios of parents.” I noted to myself that I wanted to play voices of parents who had placed their sons or daughters in institutions. I managed to play a CD from the film *Lest We Forget* on a laptop computer, and I had the security guard keep an eye on the equipment. Music accompanied the voices of the parents and other family members as they told of their experiences of visiting their loved one in the institution.

“Found new books on mental retardation—Appear to be incredibly deep for enhancing reporting of historical treatment.” Two books by James W. Trent, *Inventing the Feeble Mind* (1994) and *Mental Retardation in America* (Trent & Noll, 2004) were richly informative. Together, with my experience of viewing the evolution from warehousing people to community living, and digesting more history, I am more appreciative of the events that make up the story of this ethnographic group. Much of the history reported in Chapter 2 is from these resources.

“Awoke Saturday morning remembering boxes of Public Images Network slides in my barn.” I remembered that there was a box in the barn, from my days as president of Public Images Network, that contained 16mm films and some slides that had been abandoned when the digital age took over in presentations and training. I trudged back to the barn on a cold morning in February. I opened the plastic case of slides, hoping to find pictures to use in the exhibit. *Jackpot!* A set of 22 slides was placed in order for a training program about the move from institutions to the community, given by a legal rights organization. I photographed the slides, and then printed the images onto the silk, which went into the filmstrip frame. Some of the pictures were used in the digital viewers.

“Worked on pencil drawings all day Sunday.” The pencil drawings were to depict people in state institutions; some were not clothed, others in sad stances. Following the proposal hearing, I pulled the figures from the exhibit because they seemed too dark in mood, and out of place for the scale of the installation. However, in drawing these individuals, I felt the tone of the inside of the institution walls. The work of artistic creation can lead one into an experience that has the power to shift a mood, and evoke feelings. The drawings were not for naught.

“Printing pictures on silk—great medium. The light shines through to illuminate, like slides projected through light onto a screen.” I had wanted to paint on silk, but as previously mentioned, the building manager did not allow hanging anything on the windows, so I found that I could print computer images onto silk, which was 8½” wide, on a roll. Seeing light illuminate the pictures was very exciting. The natural light from the large windows lit up faces in the photographs, as would an incandescent light through a projector. Silk possesses a sheen that further brightens the picture. Inserting 8½” pictures into cardboard framing made to look like an oversized filmstrip created the effect of a projector light shining through the “film.” The pictures also were placed in historically chronological order, moving left to right, and were so large that the viewer had to move on down the row to view the whole piece. I am most pleased with having manipulated these materials to create this effective element of the installation.

“Doing this makes me want to paint.” Being creative is absorbing. Using materials artistically in one way can lead an artist to desire experiences with other mediums. It having been some time since I had painted—nearly one year—I was moved to pull out paints and begin to express myself. I experienced Csikszentmihaly's elements of the creative experience (listed in Chapter 2) while getting lost in creative work.

"Up in the middle of the night, working on exhibit—there is so much history—pare down! Create timeline: find specifically developmental disabilities historical moments to highlight."

The night that I wrote this, I created the notes on the index cards that pinpointed important events in the timeline of the disabilities rights movement. I used text and Internet searches

to find the legislation and public events that were on colorful index cards. These were mounted above the timeline-filmstrip, to provide information for the viewers. A sample of statements are listed below:

> "In the 1930's, sterilization become common as a way of managing populations of "the feeble minded."
>
> "In the 1960's, exposes of state schools and institutions alerted the public to poor conditions."
>
> "In 1992, John Hockenberry was refused admission to a theater in NYC because he used a wheelchair."
>
> "Three phases of DD (Developmental Disabilities) housing history: Institutional Life, Group Homes, SL Homes."

"Met Cathy, PR person for county. She helped me to be excited, instead of intimidated, about the space. Cathy was lunching with the County Treasurer; Miami Valley In-Ovations paid $60,000 for ½ of the year in property taxes! Met with

Carolyn Rice, Treasurer to appeal to get tax exemptions.*”* It was serendipity, to meet the person
responsible for the space on the same day that I had planned to meet with the County Treasurer, and the fact that the two had lunched together.

“I can’t wait to show the exhibit to… (list of names, as below).” I had listed, in my field notes, people to whom I was anxious to show my installation. Just the act of listing these vital players in this community action caused me to recall the many times resistance has been a challenge, and how they played a part. Some of the following are the people and our corresponding experiences.

“Roberta Longfellow, Community Development, told me about ‘Good Neighbor Agreements.’ ” Roberta, nicknamed “Bert,” stopped by to gaze at the exhibit and talk with me on March 26, 2011. She had helped me with many housing discrimination incidents in the county. Bert has a beautiful spirit of harmony that shows in her face. She told me about a case of changing minds about the housing development agency for low-income apartments that was negotiated just last spring. Bert announced her retirement and invited me to both of her retirement parties. I feel a real loss, as she was a strong advocate in the county system, having processed federal funding for MVIO, and was always willing to discuss the discrimination we were experiencing.

“Deb Feldman, County Administrator.” Spoke with Deb at Roberta’s retirement recognition, after the state senator gave their token of appreciation to Roberta in the form of a declaration of appreciation. I sought Deb out, just to ask her if she had seen the exhibit in the main lobby, downstairs in the County Administration Building. She had, and was full of accolades. She asked me about the status of the zoning study. A flood of memories came to me about a time when I had been experiencing a peak moment of housing discrimination. Deb had invited the many parties involved in the political arena of housing, and city and township officials to hear our problems of resistance. She is always sharp, well-dressed, and well-spoken, and she is able to bring people of different opinions together. I like harmony, but had been quite frustrated with the resistance. As I walked out of the meeting with Jim McCarthy, I recalled, we both realized how diplomatic Deb had been in the meeting. She had suggested that we ease into the zoning change recommendations so as not to jeopardize the Human Services Levy coming before the voters that fall. Jim and I looked at each other, and at the same moment it seems, we realized that both of our agencies receive over 50% of our budgets from the county. We had to follow her strong suggestion. We shared the feeling of “elbows being pinned,” after being told to ease up on the pressure to change zoning codes, until after the levy. Of course, the levy passed, so we all kept our jobs. After these memories played out in my mind, I refocused on what Debbie was saying to me, there beside the retirement cake for Roberta. “We are ready to roll, with recommending those zoning changes,” Deb said. I was reminded of the politics of community leadership by Deb Feldman’s carefully orchestrated timing, and I breathed a sigh and nodded.

“Jane Voisard, Architect.” Jane is an architect who has experience in accessible design and building regulations. She liked my exhibit, and commented in writing on the pad. I was surprised when she wrote that “people do not like change,” and she told me that minds probably cannot be changed. Jane, however, is sage. She is well known in the local architectural scene, having once been chief building inspector for Montgomery County. She is an expert at accessible architectural design and feature, so MVIO retained her to design the accessible duplex on McSmith Lane that we had built last year. Jane sat with me at the front of the Harrison Township Hearing Room when the neighbors on McSmith expressed their fears and words of resistance. She was invited because the surrounding neighbors had challenged not only the zoning, but also the placement of the building and the design. I remember noting on the eleven o'clock news, the night before the hearing, that Harrison Township had just put their fire chief on administrative leave on charges that the firemen had been watching pornography during their shifts at the firehouse. I had thought, "They have 'bigger fish to fry' than the concerns of the people on McSmith." So I was surprised at the large turnout at the meeting that next night.

The neighbors charged the architect of designing a building that is different from their fifteen-year-old duplexes, which happened to be owned by most occupants. First on their long list of complaints was the placement of the building: one foot into the setback. They shouted, "It is supposed to be 30 feet. You built it 29 feet back from the street!" The zoning director assured the audience that it had been officially inspected for compliance. These neighbors had called the police on numerous occasions, complaining that the construction crew was parking on the street. The police chief was angry at having to respond to the calls, which resulted in no violations because it is a public street. The true issues of resistance were not brought up until complaints of building violations were put to rest. They asked about supervision of the women who would live there, so when the caretaker role was explained by Pete Roll, Director of

Resident Home Association, and an actual group picture of the future residents was circulated, we heard, “Oh, they look like they are our age.” Faces seemed to soften after that. As the list of complaints was exhausted, and the people were told by the township zoning administrator that MVIO’s new duplex was within regulations, people began walking out, with seeming resignation.

Prior to the occupants moving into the double, I showed it to my daughters one day last summer. Some neighbors were in their yards, so I invited them in to see the building. A couple of women went through, seemingly impressed as they looked around, and said that they wished their homes were like ours. One told me that she really did not have a concern; it was her husband who was concerned. I heard this kind of comment a couple of more times over the past year on McSmith Lane: “It wasn’t me! I didn’t have a problem with this home.” Our tenants now love their beautiful wheelchair-accessible home, and we take care to keep the landscaping in top shape.

“Terry Welker, architect who helped us with Kettering City Council.” I ran into Terry at an outdoor sculpture unveiling as I was designing the project. I was excited to see him, hoping to get some ideas for my exhibit, as Terry is a sculptor, as well as having the full-time job of building inspector for Kettering. He had designed an accessible kitchen at one of our homes. Terry suggested that information is vital to people understanding the population that we serve. He said, “Anything you can do to help your tenants mingle with neighbors will help them (the neighbors) to feel better. They need to know that they are just people” (personal communication, March 4, 2011). I do not believe that Terry saw my exhibit, but his words came back to me often during its creation.

When we opened the Lincoln Park home in Terry's jurisdiction three years ago, Terry shared that he was embarrassed at the ugly words of resistance expressed in his City of Kettering. I was required to request a conditional use permit for the use of the home as a supported living home for four men. The street is a boulevard situated behind the high school and down the street from a beautiful city park and pavilion at which outdoor events are held. Kettering's reputation is that of a model city that prides itself on its fine schools. A retired school principal that lives on the street expressed especial prejudice in his letter to the city, complaining that MVIO was going to violate the city's zoning code by renting to people with mental retardation in a group home model. Terry and his colleagues called me to ask that I comply with their outdated zoning code and apply for the permit, which they had not required for our five other homes in Kettering. Permits require public notice and a public hearing. Neighbors are notified of the meeting and may testify. I presented testimony, which described my role as landlord, told about the model of giving choice to the individuals through supported living, and assured them that we have a fine lawn care crew. I ended by encouraging the council to change their zoning code. Residents of surrounding houses publicly expressed their fears and their resistance, but the zoning permit was approved. Outside the meeting afterwards, Terry made a point of assuring me that my testimony was well done, and that their legal director was working on the zoning changes that would prevent this type of situation in the future.

One of my interviewees is a neighbor of our home on Lincoln Park Boulevard. Shirley happened by my exhibit. She is not happy that MVIO bought the home and rents to people with developmental disabilities, but she seemed to appreciate an opportunity to be heard. See the Shirley L. interview in Chapter 4.

“Jim McCarthy, CEO, Miami Valley Fair Housing Center (MVFHC).” Jim McCarthy is not only a strong advocate of our work but is also on MVIO’s board of trustees. He helps me by providing advice, and sometimes legal counsel, regarding the right to fair housing for people with developmental disabilities. “Jimmy,” as his friends call him, is an affable, energetic fellow, who seems to know everyone in the county and a number of officials in Washington, D.C. He is known for not backing down in a battle for affordable housing.

Jim has provided advice and been next to me at every public hearing regarding zoning since I have been in this position. I have had to go to these meetings too many times to count. This is an indication that the zoning codes in the county are out of compliance with the Fair Housing Laws.

Jim always testifies about fair housing in these meetings. He defines supported living for officials and declares the right of people to choose to live in the community just as any other citizen can. Jim has encouraged me to vocally testify at these official hearings, and he has also held my shoulders to *prevent* me from speaking out at times. Always having an audiotape stuffed into his sock, he does not stop a jurisdiction from implicating themselves in a fair housing violation. When Harrison Township denied a conditional use permit for us to rent the fourth bedroom in our four-bedroom house last year, Jim proposed to the MVIO Board to file a complaint with the Ohio Civil Rights Commission. A very well-orchestrated set of eleven testimonies from neighbors opposed to our request for a conditional use permit was successful at the Harrison Township Public Hearing in 2010: Permit denied, the ruling was upheld that states, “No more than three persons constitutes a ‘family’ in single-family housing in Harrison Township.” The president of the Zoning Board actually commended the neighbors who testified, saying, “You are fine citizens of Harrison Township. Good job. We vote ‘No.’”

Since MVIO and the MVFHC filed the civil rights complaint in Harrison Township, the word has spread. This past year, the MVFHC published guidelines for changing zoning codes to come into compliance with the Fair Housing Act, as amended. The organization also provided a table listing all of the jurisdictions and parts of the codes that are discriminatory. The cities and townships are working to change their codes, which is a lengthy process involving public notices and hearings.

Jim believes in using the law to enforce rights to fair housing, and is opposed to “asking permission,” as in the public hearings for the conditional use process. Nor does Jim favour a public information session, held by MVIO or the County Board of Developmental Disabilities to introduce our future tenants to the neighbors. He clearly believes that we should not ask permission for people to exercise their rights to live where they want to live.

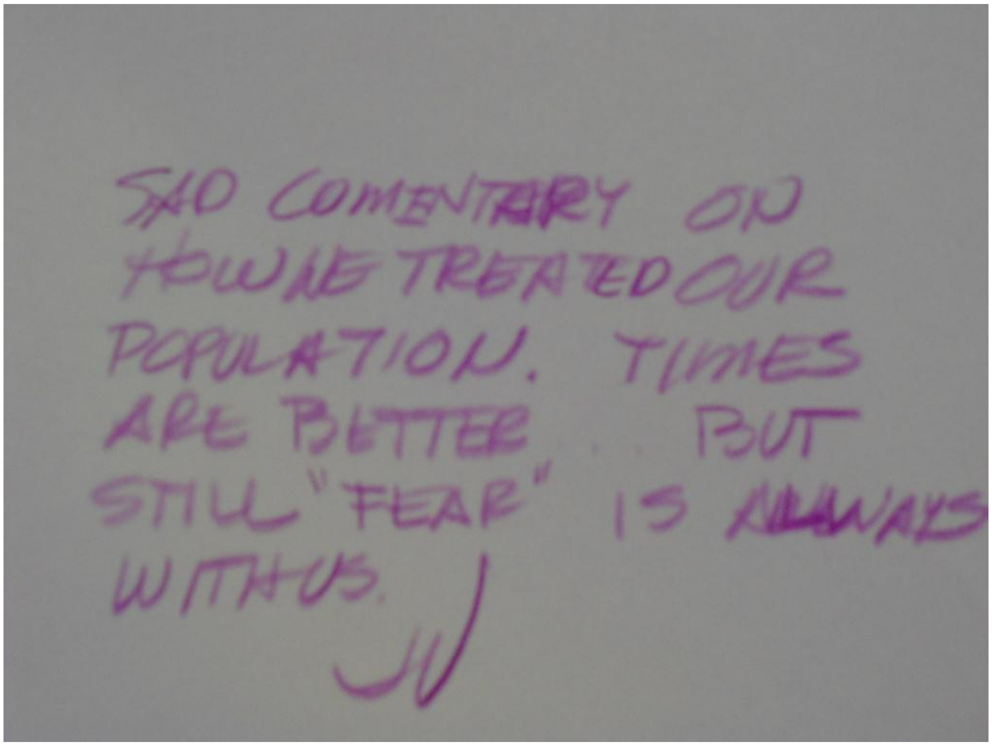
Just eighteen months ago, I was embroiled in opposition in three different neighborhoods in three different jurisdictions. Because I had purchased these three homes for four people to rent each, I had dramatically upset people in these neighborhoods. They were concerned about property values, safety, handicap vans using the streets, etc. I roughly figured that, at that time, I was upsetting 60 people just by doing my job. By creating much-needed housing for people with developmental disabilities, I had stirred up the lives of the residents on the three different streets, as well as the public officials who dealt with the complaints and the legalities of housing. Jim McCarthy, by doing his job, has helped me by working to prevent the formal procedures that invite neighbors to gather at a public hearing, forming collective opposition. Awareness is necessary for acceptance, but legal barriers to fair housing need to be removed, before full integration can occur.

I have presented a sampling of my field notes, those that I deemed important for the purposes of this paper. Emerson, Fretz, and Shaw (1995) address the style in which I have presented this selection:

> In writing field notes, a researcher not only remembers and envisions a scene; he also presents that scene from a selected angle which highlights some of its features more than others. This angling results in part from theoretical concerns of the researcher's discipline; it also results in part from the nature of his participation in the field—for example, from his inevitably selective positioning and from identifying with certain members' experiences. The selective tendencies of field participation and memory construction are supplemented by the fact that ethnographers, like all writers recounting events, must unavoidably tell their story through their "point of view." (p. 53)

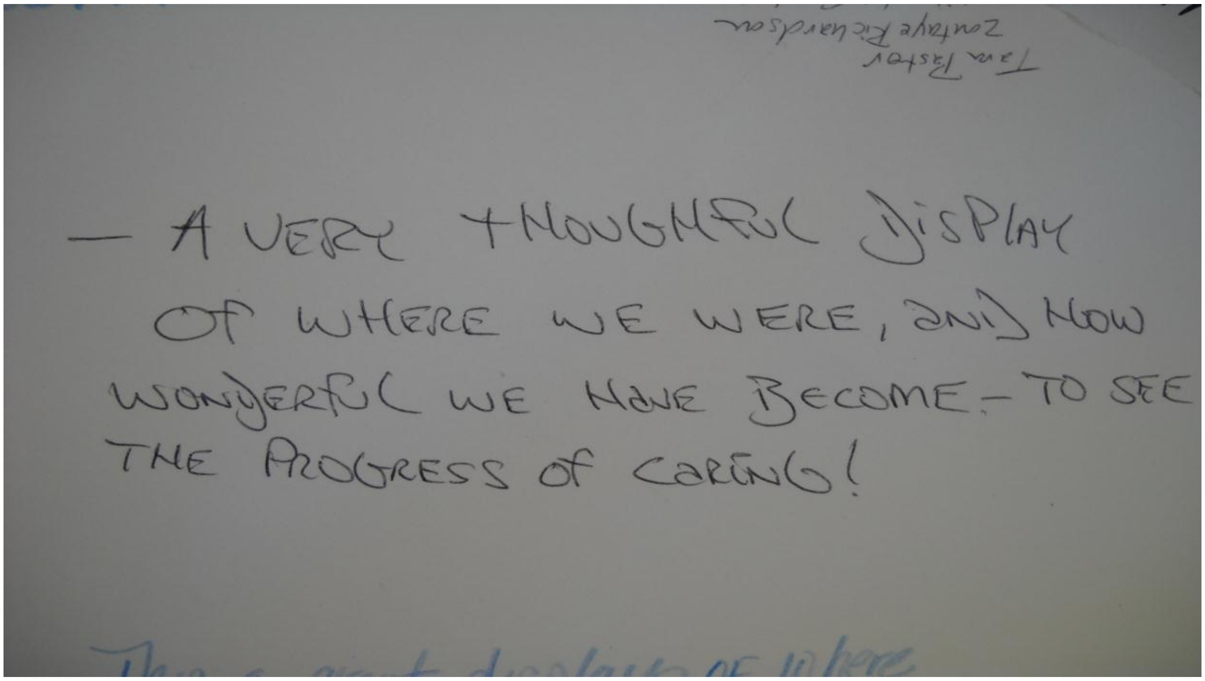
Comments

I sought the public's reaction to the experience of viewing the exhibit by providing a pad of art paper and colored markers. I was thrilled at the response from many participants. As seen in Figure 4.15, some saw the opportunity to compliment the work. However, many comments seemed to come from a deep and thoughtful stirring of the heart.



SAD COMENTARY ON HOW WE TREATED OUR POPULATION. TIMES ARE BETTER BUT STILL "FEAR" IS ALWAYS WITH US.

Figure 4.15 Comment from viewer on art pad

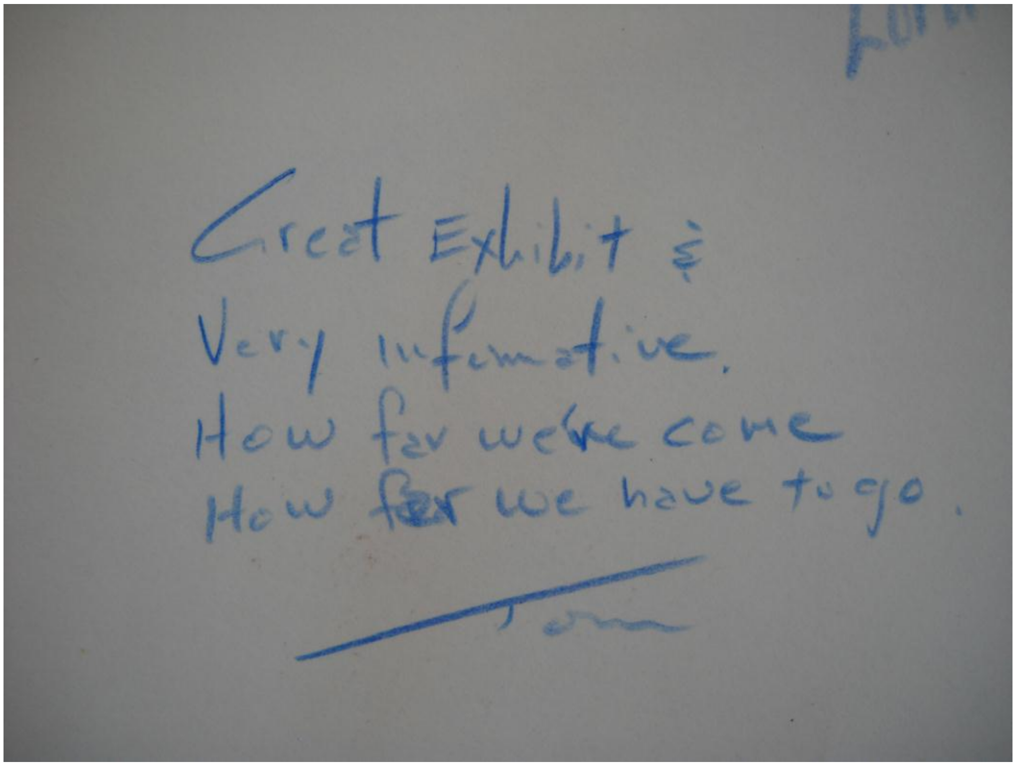


Tara Paxton
Zontaye Richardson

— A VERY THOUGHTFUL DISPLAY OF WHERE WE WERE, AND HOW WONDERFUL WE HAVE BECOME – TO SEE THE PROGRESS OF CARING!

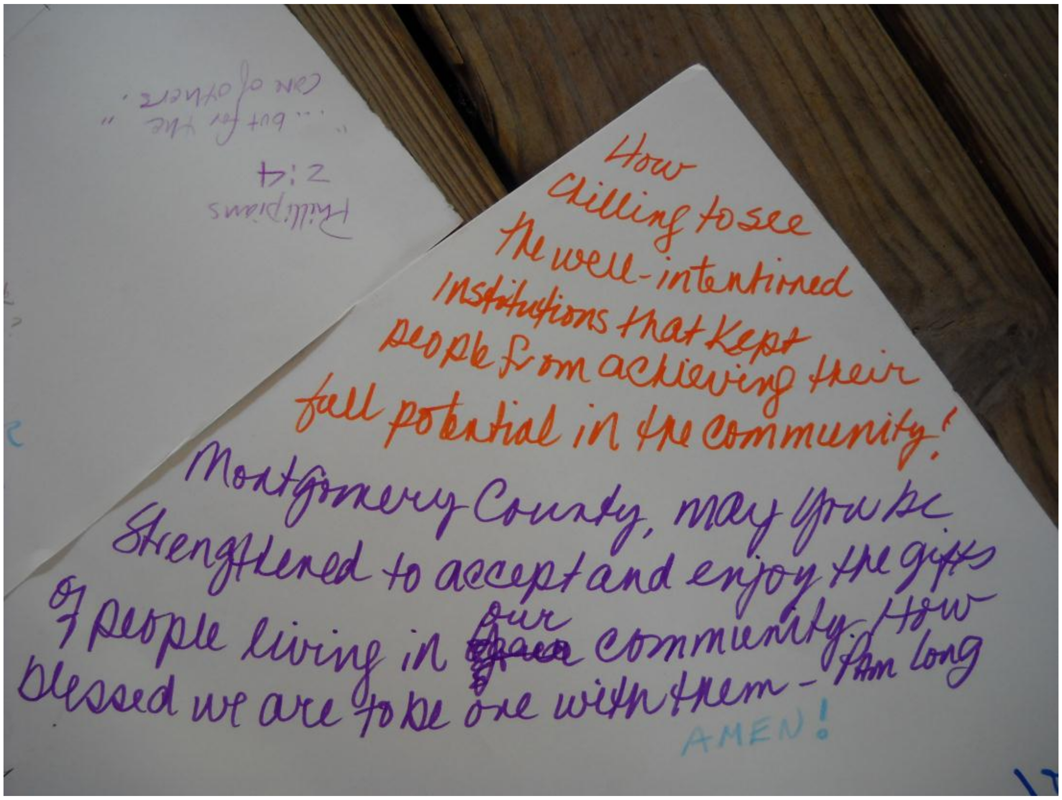
This a great display of where

Figure 4.16 Comment from viewer written on art pad



Great Exhibit &
Very informative.
How far we've come
How far we have to go.
Tom

Figure 4.17 Comment from viewer written on art pad



Phillipians 2:4
"... but for the care of others."

How chilling to see the well-intentioned institutions that kept people from achieving their full potential in the community!

Montgomery County, may you be strengthened to accept and enjoy the gifts of people living in [illegible] our community. How blessed we are to be one with them - Pam Long

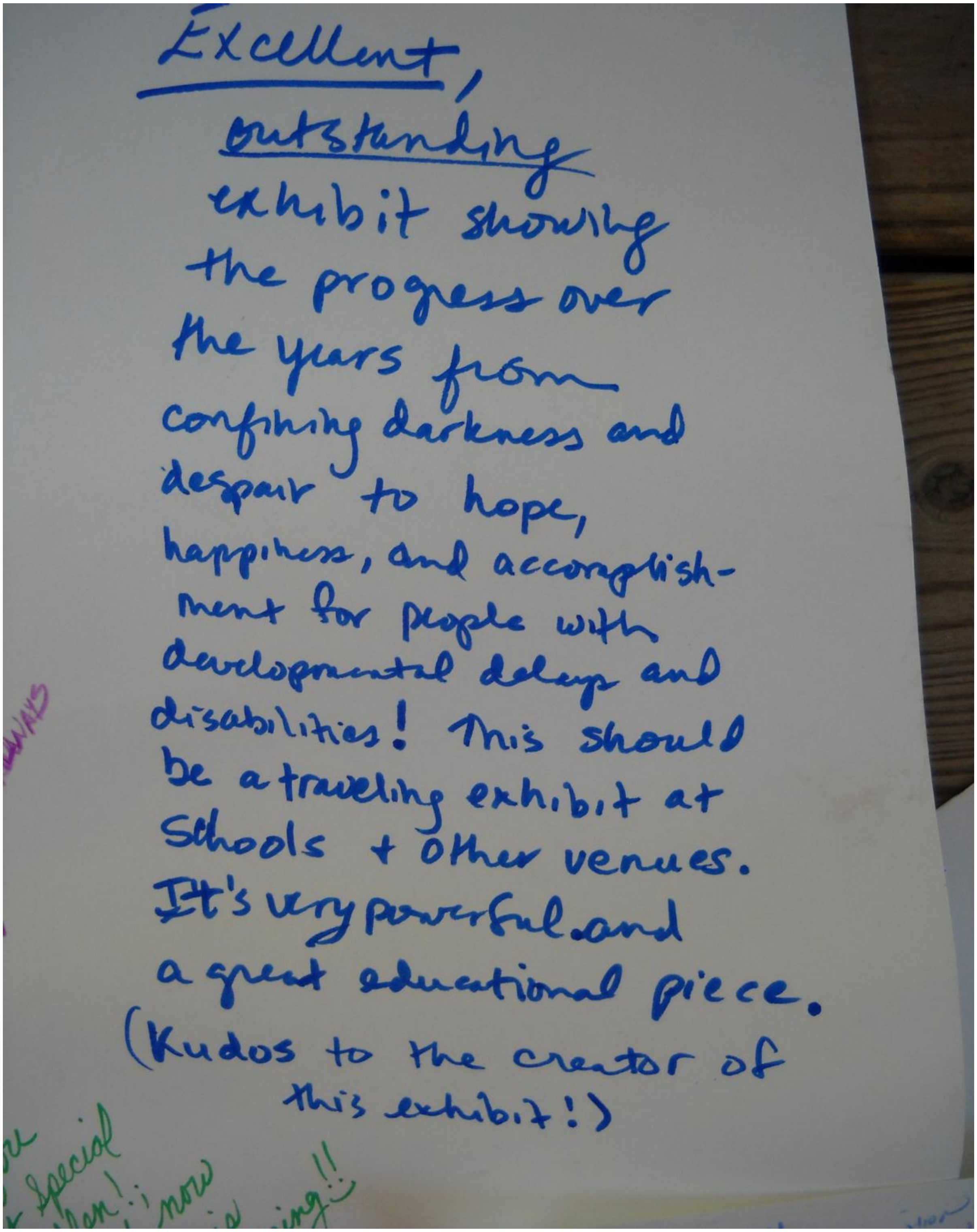
AMEN!

Figure 4.18 Comment written by viewer on art pad

Another comment on the art pad said:

> "I can write a book on my frustration with my experiences with the school system regarding IEP and the neglect of accountability for Hearing Impaired and other disabilities. There is a lack of creativity in classrooms. To me, the care is not given and extra interpretation, directions, or rephrasing is not being used. Children are not being challenged. All disabled are being stereotyped. Not much has changed today. Learning styles of people are different. All need to be able to be taught. All neighborhoods nationwide need to be educated now, today."

I



Excellent, outstanding exhibit showing the progress over the years from confining darkness and despair to hope, happiness, and accomplishment for people with developmental delays and disabilities! This should be a traveling exhibit at schools + other venues. It's very powerful and a great educational piece. (Kudos to the creator of this exhibit!)

Figure 4.19 Comment from viewer written on art pad

In addition to the pictured comments, the following are more written comments:

"The bottom line is, these are humans and we can't just throw them away!"

"Eye-opening display. We've come so far, with further to go!"

"This display was very informational. God Bless everyone who has lent a helping hand to the disabled community."

"Very nice display. More awareness and support are a great thing! It's a civil rights movement that is not over."

"We have come a long way. Thanks for showing us the past and the better of today."

"Homes, not nursing homes!"

"Nice display—great progress. Keep going forward with any and all improvements possible."

"Creative. Thought-provoking. Powerful."

"A society is judged by how it treats the young, the old and those in the shadows. Great display!"

"God Bless the people who make it possible for the disabled, who fight to keep them alive."

"God Bless all of you, for doing what you do to help people with Disabilities. I'm raising my nephew who has Down's Syndrome. This exhibit is awesome and knowledgeable! Thank you."

"Great visual impression of evolving care of our citizens!"

"I am thankful for all you do."

"Good history lesson"

"What took us so long?"

In small conversations around the exhibit, I heard:

"I was shocked to hear the people labelled 'idiots' and imbeciles!' I won't throw those terms around anymore."

> “People don’t like the term, ‘group home.’ Maybe people would accept them more if they knew the individuals. Could you have open houses, each time you moved people in?”
>
> “As an architect, I have built homes for people with dual diagnosis coming out of Orient State Institute. I don’t think that you can change minds. If they don’t have relatives with developmental disabilities, the neighbors have a fear of these people who are different.”
>
> “You should call the local PBS station. They should do a piece on what you do!”

In “small conversations,” viewers revealed poignant thoughts, which further informed me, as in the following example:

One conversation that I had was with a ten-year-old young man named Zayshon. He was very inquisitive. “What is this about?” I pointed out the model of an institution, the ward vignette, the bars on the windows. I mentioned that sometimes people were neglected and abused in these places. He said he’d been in a hospital that looked like that (the model) and his mother stepped up to tell me that he had “special needs.”

Later, the boy asked me, “Did they go to jail?”

I asked, “Who?” And he said, “The people who abused the residents. Did they go to jail for what they did?”

I carried that question back to work, and recollected with colleagues who had also worked in institutions. No one remembered anyone who was legally prosecuted for abusing people in institutions, even though abuse was often substantiated. Disciplinary action was the most we had witnessed as a consequence for abusing residents, and on at least one occasion, the union representing the individual appealed the disciplinary action given an employee charged with abuse and he was allowed to return to work with full back pay for his administrative leave. Today, in Ohio, abuse and neglect are grounds for dismissal, potential conviction and incarceration, and placement on a list called “The Abuser Registry,” so the abuser is never hired to care for people again.

Interviews

A small, selected group of individuals who viewed the exhibit were interviewed for a deeper response to viewing the exhibit. In-depth interviews added feedback to the data. I conducted interviews with five participants, chosen to represent different perspectives. The interviewee participants answered a set of questions regarding the exhibit. The style of interviewing was that of a structured conversation, with open-ended questions. The intent was to gain feedback about the impressions the viewers experienced. They were given the opportunity for deeper, more reflective responses than what was possible on the comment paper. Questions asked were the following:

- What “sticks with you” about the installation at the county building in March?
- Do you recall any feelings that the exhibit evoked, while viewing it, or at a later point?
- Do you think that this exhibit had the capability of making an impression on the general public viewing it?
-
- Did you choose to engage in commenting on the pad provided for impressions?
- What prompted you to comment?
- Did you read any other comments?
- Did you intend for others to read your comments?
- What else would you like to add to our reflection on the exhibit?

Each viewer/participant signed a form entitled “Consent to be Interviewed.” The consent indicated that the interviewee’s responses would become part of my published dissertation. I had IRB approval for conducting the interviews of viewer/participants.

The risk of potential emotional reaction was indicated in the consent.

The representative viewers of the installation were chosen to represent different perspectives, as noted previously. I had considered their positions to be different because I had an indication of their perspective toward the subject matter. This list of interviewees corresponds with the order of the interviews and responses:

1. Teresa: Passer-by/Sympathizer
2. Steve and Nancy: Supportive neighbors of a supported living home
3. Shirley: Not so supportive neighbor of a supported living home
4. Latisha: Tenant of a supported living home
5. Mark: Administrator of county program

Interview 1 – Teresa Susberry. I chose to interview Teresa Susberry because she seemed so moved by the exhibit. She made a point of returning to talk with me after seeing the installation on her lunch break. She noted that something she had on her desk was apropos and wanted to show it to me. *The Daily Bread* inspirational message for the day was from the Bible, Philippians 2:4, “Look not every man on his own things, but every man also on the things of others” (Bible, King James Version). Teresa said that she does not like to proselytize, but is interested in fairness and equality. She thinks that officials knew people were being mistreated, but chose to turn a blind eye. When I later interviewed her, I asked, “What ‘sticks’ with you about the installation at the county building about people with developmental disabilities and their treatment?” Teresa replied:

> “I reflect on the display of what the living facilities were like over 30 years ago, and what the options are today, and I wonder “why”? Why were these innocent individuals being treated as if they were criminals? Why does it seem as if they were being punished and locked up in institution style “homes,” just because they

> were born different than what America deems to be normal? What about their individual rights? The laws were not set to protect everyone's human rights, the laws were biased. It appeared to be the "out of sight-out of mind" cliché."

Teresa recalled that, when she was growing up in Cleveland, Ohio, "The 'crazy house' was up the hill—Fairhill. The neighborhood tease was that 'you would be sent up the hill,' if you didn't act right." Fairhill has since closed and Teresa remembers that patients were left "on the street to fend for themselves." Teresa was able to tell me about Fairhill having closed because her thoughts about it had prompted her to do an Internet search. She took the time to send me the following, the day after the interview:

The **FAIRHILL MENTAL HEALTH CENTER** (1959-Dec. 1983, originally Fairhill Psychiatric Hospital) was a state psychiatric facility in Cleveland dedicated to intensive, short-term care. It opened as one of 5 state psychiatric facilities in Cleveland in the former U.S. MARINE HOSPITAL on Fairhill Road. Although Fairhill originally had a capacity of 200 beds, by 1960 only 70 were in use because of staffing problems. With the enactment of the Community Mental Health Centers Act by Congress in 1963, the name changed to the Fairhill Mental Health Center. Its overall purpose was slightly revised, "to provide comprehensive psychiatric services to all residents of a given geographical area, regardless of socio-economic status," but its emphasis remained on short-term care. (Its service area consisted primarily of Cleveland's east side and eastern suburbs.) Fairhill attempted to minimize many of the negative aspects of state mental hospitals, with a cheerful and bright interior and innovative therapeutic programs which encouraged patient involvement. In 1966 Fairhill became one of 3 "open hospitals" (no locked doors) in the country.

From the mid-1960s, Fairhill suffered from budgetary restrictions and changing state directives. One result was overcrowding: in 1966 admissions were limited to only 50%, because of delays in transferring patients to long-term hospitals. In 1975 a budget crisis resulted in the transfer of 38 employees to institutions for the mentally retarded; two years later, the hospital's out-patient clinic closed. Despite a $3 million

> renovation in 1980, overcrowded conditions persisted; the hospital was criticized for early discharges. By 1983, not meeting federal standards, it was in danger of being decertified for Medicare and Medicaid. As the Cleveand Psychiatric Institute was in a similar situation, the Ohio Department of Mental Hygiene & Correction consolidated the two and closed the Fairhill Mental Health Center. In 1989, the property became the home of the Fairhill Center for Aging, a joint venture of the BENJAMIN ROSE INSTITUTE and UNIVERSITY HOSPITALS CASE MEDICAL CENTER. In 1995, the site was named a Cleveland Historic Landmark, receiving more than 1,200 visitors a month as of 2002.
>
> Reference: http://ech.cwru.edu/ech-cgi/article.pl?id=FMHC

Teresa also was reminded about a boy in her neighborhood who was called "retarded" and whose family kept him at home throughout his life. Reflecting on her life experiences with people with disabilities, Teresa cited two examples that had made an indelible impression on a young person. "Like many others, I was ignorant to the true facts associated with many aspects involving disabilities. I am now able to correct the stereotype messages that I was exposed to at an early age, by educating myself," she said, and I thanked her for sending the information on Fairhill.

I asked Teresa the question about whether this exhibit had the capability of making an impression on the general public viewing it. She said, "Now when I come in contact with individuals with disabilities I can have some form of genuine connection to their life struggles, other than the obvious; if I am up against making a decision to vote 'yes' or 'no' on a levy involving disabilities, I can make a conscious choice based on the reality, not the visual assumption." With this statement, Teresa showed that she had made the connection between compassion and voicing support through the payment of taxes.

When asked about what had prompted her to comment on the pad of paper, Teresa said, "When it was explained to me about the resistance of some communities to allow disabled individuals the freedom to live wherever they choose." She wrote the following, on the art pad:

> Even though we are not all faced with the need (of housing), but please keep in mind that as we love our neighbor and as we are our brother's keeper, this (exhibit) is showing us all how to be a little bit more human. Your neighbor can never hurt. Thank you! (Comment by viewer, March 17, 2011)

When I asked Teresa if anything resonated with her, after leaving the installation, she put her thoughts into a series of questions:

> "What if it was your loved one? Where do you expect them to live? Do you believe that they have the right to live a free, normal life? Do you believe that they deserve to live independently, if able? Do you believe that they should have the same human rights as everyone else? Do you believe that their caregivers (parents/guardians) deserve to have a peace of mind knowing that their loved one is in a safe environment? In today's market wouldn't you rather the home in your community be occupied and well maintained by the owner, like, the possibility of being vacant and dilapidated?"

Teresa had put much thought into her responses. She made connections with her past and present life experiences. Via courier in county interoffice mail, Teresa sent me a copy of handouts from an in-service that she had recently attended. The program was called "The Ten Lenses" (Williams, 2001). The handout addressed cultural diversity, stereotypes, and cross-cultural experiences. Teresa's notes at the bottom of one page said, "We look at other cultures through our own cultural lenses." She seems to be a person who values lifelong learning, as demonstrated by her attending programs such as this. Prior to meeting Teresa at the exhibit in March I had not known her. She works in the Office of the Montgomery County Treasurer, in the building where the exhibit was held.

Interview 2 – Steve and Nancy Huff. Steve and Nancy Huff live next to a home where four women with developmental disabilities share the rent of a four-bedroom house. Both Steve and Nancy chose to be interviewed, together, because they both wanted to give input. They had strolled through the exhibit when I was not present, but commented on it when I was talking to Steve about fallen branches in our property's yard from a recent storm. Nancy told me in the interview that she was curious when our tenants had moved in three years previously. She reported that, upon seeing construction workers renovating the home for wheelchair accessibility, she watched the activity and wondered. When the moving vans appeared, she went to the house next door to meet the new neighbors, offering cookies and lemonade. At the time, the parents of the young women residents were setting up the home, so Nancy met her new neighbors *and* their families. Meeting the women's mothers, she said, helped her to understand the need for a home with services for the individuals. She realized that "the unknown is worse than knowing who is moving into a home in your neighborhood."

When asked what feelings each witnessed upon seeing my installation at the county building, Steve first said that he noted that the first part made him feel sad, but he felt joy at seeing the transition to smiles and warmth at the end. He was reminded of the old children's homes that housed the orphans in each county. Nancy reported feeling sad that "humans were treated that way." She shared that she had an aunt who had disabilities and was not institutionalized, but that her family in Kentucky kept their daughter at home and "took on the job of starting a sheltered workshop in the area, which still exists."

Both Steve and Nancy responded to the question about the exhibit's ability to make an impression on the general public with doubts that people took the time to see and absorb the messages. Steve said, "It takes a personal touch. Getting to meet a person with disabilities and putting themselves in the situation may help them understand. For instance, the guys who work at the grocery stores, bagging… I try to get in the line with Joe, who is always smiling." Nancy thought the exhibit with visuals was a "great start, with its ward scene."

Steve and Nancy told me about interaction with the residents next door, of which I had been unaware. The women have come to their children's birthday parties, and Nancy "loves the concept of blending their kids together with the ladies." She relayed that she actually wishes they had more time for those sorts of interactions.

They noted, however, that the neighbors on the other side had erected a six-foot privacy fence only at the intersection of the properties where our tenants live. Steve said, "Society is more closed. Privacy is more prevalent today. We have always wanted to meet new people, but people just don't seem to be that way anymore."

Steve and Nancy did describe two events with their neighbors with disabilities, which are minor annoyances. Firstly, the bus with handicapped features that picks one woman up daily has back-up beeps that are very loud, and it backs into the driveway at 7:00 a.m. Also, they feel that the caregivers should be more aware of the neighbors' standards, like picking up fallen branches and trying not to make tire ruts along the sides of the driveway.

Interview 3 – Shirley L., neighbor. Shirley works in the county building, and happens to live near to a home that my agency owns, where four men reside. She had talked to me at the exhibit, so I thought that interviewing her would help me to understand her perspective. Shirley, who did not want me to use her last name, relayed to me that she was attracted to the installation because she saw the pictures of the homes and people. She had said to me at the exhibit, “I have a home like this in my neighborhood.” I recall that when I asked where she lived, and she said, “Lincoln Park Boulevard.” I affirmed that it is one of our homes. She then took a step back, folded her arms, lowered her eyelids a bit, and said, “Oh, so you were the woman talking to the city council. I was at that meeting. Next door, the Rasers, they paid too much for their home, so they are still upset about your group home lowering their property value.” She said that concerned neighbors tried to tell the city council not to allow our home to open there. “I just don’t think it should be there. I knew the former owners. They were both professors. I hated to see them go.”

Asked about the exhibit’s ability to make an impression on the general public, Shirley said, “Yes,” but asked why public dollars have to support the individuals with disabilities. “Don’t they have families? Why don’t parents pay for their keep? People resent that public funds support these people. My daughter has to support herself. She’s at college, and she can’t even get insurance on her own.”

In honoring the open interview style that I had chosen, I let Shirley express her concerns, while I remained consciously aware of my posture so as to appear open-minded. Shirley’s comments again referred to the parents of the men living in the home, and when I said that some of our tenants do not have family, she said, “Don’t they have some kind of insurance or something?”

I thanked Shirley for talking with me and intentionally brought up a memory of an event that had impacted the neighborhood two years ago: Hurricane Ike’s winds that reached Ohio. The men in our home had helped to pick up branches in neighbors’ yards. Shirley said that she had offered to pick up groceries for the men because their house was without electricity at the time. I thanked her for that kind gesture. When I departed, I reflected on her words and gesture, and how she has been neighborly, having been concerned about the Rasers' property values, but also our tenants' welfare after the windstorm. However, her reservations about the supported living home's location dominates her thoughts regarding people with developmental disabilities and how society should (or should not) provide services and housing.

Interview 4 – Latisha Martin, tenant, and Vicki Wagers, personal care attendant. Latisha was mentioned in Chapter 1 as being one of my heroes. In my mind, her responses to my questions in the interview affirmed her standing. Latisha began sharing personal information with me when first called about the interview. She is a tenant in one of the homes that my agency owns and manages. In fact, I had purchased the duplex and contracted to have it remodelled for accessibility for Latisha and three other residents. We had shared ideas about my exhibit because I wanted her input. Since she is an advocate, she knows how to represent people with developmental disabilities with dignity. When Latisha saw the installation, I was both eager and pensive while observing her expression, concerned that she might judge me.

When asked what "stuck" with her after seeing the exhibit, Latisha reported that seeing the model of the state institution ward made her glad she had not been born earlier. She thought it was, in her words, "really dark and hard." She said that she had a low opinion of families who dropped off their children at institutions, and recommended a book to me, *Sewing My Tears, Reaping His Joy*, by Mariah Wicher.

When asked if the exhibit had the capacity to influence people's attitudes, she said, "Possibly. If neighbors were educated, than I think they would truly like us. But they better not fake it. I don’t like actors. But, they need to realize (that) we are people. We just need the best quality of life possible.”

At this point, I learned that the personal care attendant with her during the interview had also seen the installation at the same time. She offered some comments of her own, and I recognized this as a bonus. Vicki, as she would like to be identified, shared that when she was a staff member of another one of our newly opened homes, the residents and their families held an open house. She was disappointed that no neighbors came, in spite of flyers being distributed throughout the neighborhood. She said, “People are afraid of what they don’t know, and we just thought if they knew the ladies, they would be more accepting.” Vicki, however, admitted that the woman who lives next door to Latisha, a double home located in an entirely different area of town, waves when the residents or staff are outside. Vicki reported remembering that her aunt kept her nephew who had mental retardation inside their house at all times. Neighbors never even saw him. She was astonished when her uncle warned her years later, when she took the personal attendant job, not to “turn her back on any of those people.”

Latisha talks a lot, and had a hard time waiting for my questions. Her energy is wonderfully contagious. But she answered the questions with thought, and especially paid serious attention to the matter of acceptance. The last thing Latisha said, at the end of the interview, was, “Your exhibit shows me how blessed I am.” She said that she is twenty-eight years old, and she is glad not to have been in an institution. She reported having been abused by her biological family, despite the fact that she uses a wheelchair because cerebral palsy has caused her to be nonambulatory. She said that her family does not appreciate that she is living the life that she wants to live. “They won’t take the time to understand. My staff knows more about me than my family. Watch this: Vicki, how much money do I have in my account?” Vicki answered a dollar amount. “See!” Latisha said. ‘What did I tell you? She always knows!”

Interview 5 – Mark Gerhardstein. Mark is the superintendent of the Montgomery County Board of Developmental Disabilities. He has a long history of leadership in human services that includes mental in health services, children services, education, and developmental disabilities services. In Chapter 1, he is mentioned as the supervisor with whom I had discussed the initial ideas of the installation. This is one of the many reasons that I wanted him to see it. Mark is a “direct leader,” not only due to his official title and role, but also due to his “direct words or acts” (Gardner, 1995, p. 137). He had viewed the installation when I was not present, probably when he was in the building for a meeting with other county administrators, but he had written the following comment on the art pad, provided: “The Disabilities Field is a civil rights movement. Good examples of progress given—it’s not over yet, though.”

In the interview, Mark took the opportunity to offer his own version of witnessing the deplorable conditions at the state institutes in the 1970’s. I asked him, “what ‘sticks with you,’ regarding the exhibit?” Mark said that it brought back a recollection of the “hellholes” that developmental disabilities institutions were. “It was warehousing. The austerity and real pictures reminded me of how it was close to Auschwitz.” He said that I could not have duplicated the conditions on wards exactly, especially the overpowering stench that permeated the whole grounds of the institutions. He said that parents had a hard time placing their sons or daughters there. He felt that the exhibit was a true representation of progress—about the humanity of people with developmental disabilities and their families. Mark noted that “people have been letting us move into the community, into schools, and housing, but it is not over.” He spoke about the Fair Housing Laws being in place. Despite this, local zoning codes restrict housing development for people with disabilities with their wording, such as the definition of “family” being “three or fewer unrelated individuals.” When asked about the capability of this exhibit to make an impression on the general public, Mark thought that some public viewers were “shocked.” He noted this on the comments pad when he viewed the exhibit.

I asked, “What prompted you to comment?” He answered with a smile, “The colored markers.”

“Did you intend for others to read your comment?” I asked him. He admitted having written the comment for my viewing. Mark recalled our having discussed the exhibit when it was just a concept. He said, “Yes, we wanted to measure people’s expectations.”

Mark heralds the Olmstead Decision, now a guide for all states to model for meeting less restrictive environments. He suggested that I include a synopsis in this document, because this piece of legislation is currently a driving force for housing in community settings:

> The Supreme Court’s Olmstead v L.C. and E.W. was decided in 1999 and clearly stated that Title II of the ADA required states to provide services and supports to people with disabilities in “the most integrated setting appropriate.” The court found that unnecessary segregation of people with disabilities in institutions when they could and wanted to live in community settings was discrimination. (http://www.law.cornell.edu/supct/html/98-536.ZS.html)

When pondering what else he wanted to add to our reflection on the exhibit, Mark said, “Anything we can do to make people focus on experiencing the reality and humanity, then we create room for compassion.” He noted that people go on “autopilot, with their stereotypes.” Mark spoke of dignity for people with disabilities and the need for the public to “recognize the rights of individuals of all types to live in the neighborhood where their family lives, where they work and where they worship.”

Mark is proud of our collaboration on a zoning study, aforementioned, with the Miami Valley Fair Housing Center. The notion to conduct the study of the county’s thirty zoning codes to identify discriminatory restrictions was originally Mark’s. He celebrates this study as an “Unusual Positive Incident,” a term which he created as an intentional wordplay on the phrase, “Unusual Incidents,” which are typically of a negative nature. In this way, Mark demonstrates his values-based leadership style (O’Toole, 1995). O’Toole (1995) coined the term for a style of leadership in which virtuous principles guide a leader, such as evidenced in the following characteristics: “courage, authenticity, integrity, vision, passion, conviction and persistence” (p. 21). O’Toole (1995) draws these from the characteristics of four presidents in American history: Washington, Jefferson, Lincoln, and Roosevelt (the “Rushmorians” (p. 22). Mark Gerhardstein had trained for the seminary, and his devotion to humanity comes through. I believe that we share the same passion for this work because of our having experienced the old state institutions’ conditions and been driven by a need for change.

In summary, the data collected through my field notes, written comments, and spoken words in interviews were of a subjective nature. This highlights one of the virtues of qualitative research.

Reflection is a gift that humans enjoy. Thoughts from participants contribute to a study in a rich, varied way, adding to a body of data which forms a larger picture of a phenomenon. In this case, the depth of the responses addressed the inquiry about participants’ reactions.

In Chapter 5, the results are analyzed and discussion continues in the conclusion in Chapter 6.

Chapter V: Analysis and Evaluation

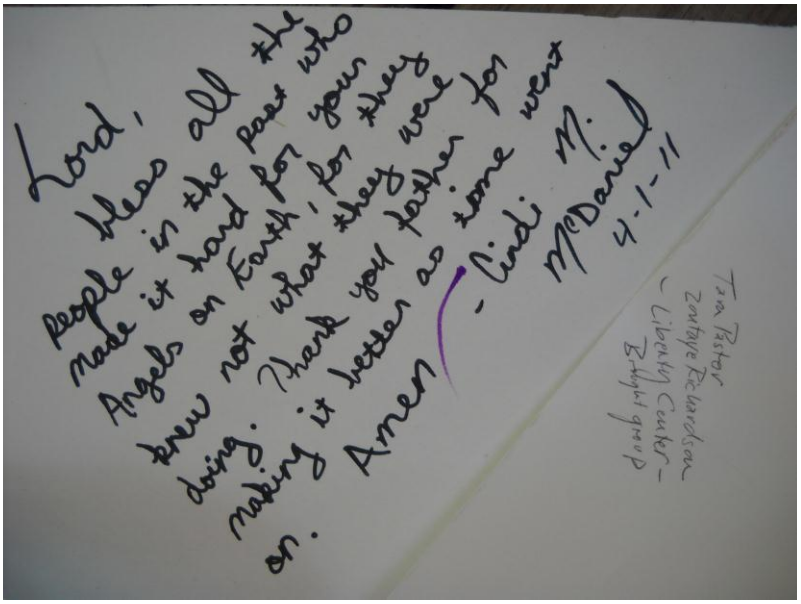
As reported in Chapter 4, data was collected from the responses in the form of field notes, written comments, and interviews. Rich responses to the installation became evident through analysis. This chapter includes a review of the topics displayed in the exhibit, an analysis of viewer responses, from which apparent themes emerged, and an evaluation of the project's effectiveness. I draw from scholarly literature such as Trent on historical perspectives, Gardner (1995) on change, Rosler (1991) on art for social change and Eisner (2012), Knowles and Cole (2008) for evaluating the use of arts based research for the methodology.

Analysis of the Responses from Participant Comments

Having participants comment in written and oral form as a means of gathering data was very effective. Responses from participants on the drawing pad that was provided and in small conversations were deep and reflective. The opportunity to share their thoughts or feelings immediately after viewing the exhibit proved to be an effective way to facilitate the participation of viewers. Many people who saw the display and took the time to comment seemed to have been moved to do so out of a desire to share their own sense of social commitment. They could have looked the other way, as do many, from the images of people who are different. In an analysis of the data from responses, I noted common themes emerging from comments: spirituality, social responsibility, and change and resistance.

The first theme, *spirituality*, was evident in viewers' references in a few written comments on the drawing pad, some of which were actually written in the form of prayers (see Figures 5.1 and 5.2). Trent (2004) reveals in his book *Retardation in*

America that providing services for people with developmental disabilities has roots in faith-based programs. In the early 1900's, Quakers became involved in a mission to provide quality care in the state institutions across the eastern United States. In the history of treatment of people with developmental disabilities across time, certain sects of Christianity have come forth to devote themselves to provision of care. Currently, many providers of services have denominational roots, for example, Lutheran Social Services and Catholic Social Services, and Good Samaritan Homes. Also, the expression "There but for the grace of God go I" is frequently used about people with disabilities. The speaker seems to be saying, "It could have been me!" This notion is a cry of gratitude for being born without these challenges. But a movement toward a new attitude is forming in the growing field of disability studies. The Ohio State University Disability Studies program teaches respect for disability. The thinking promoted by this program is one of *celebration of differences*. This directs the light away from a sense of pity and leads to one of respect for the individual who has disabilities, instead of sympathy for one who was unfortunate to have experienced an event that made them disabled in some way. Turning a multifaceted gem to another perspective often allows one to see it in a different light, as the data depicted.

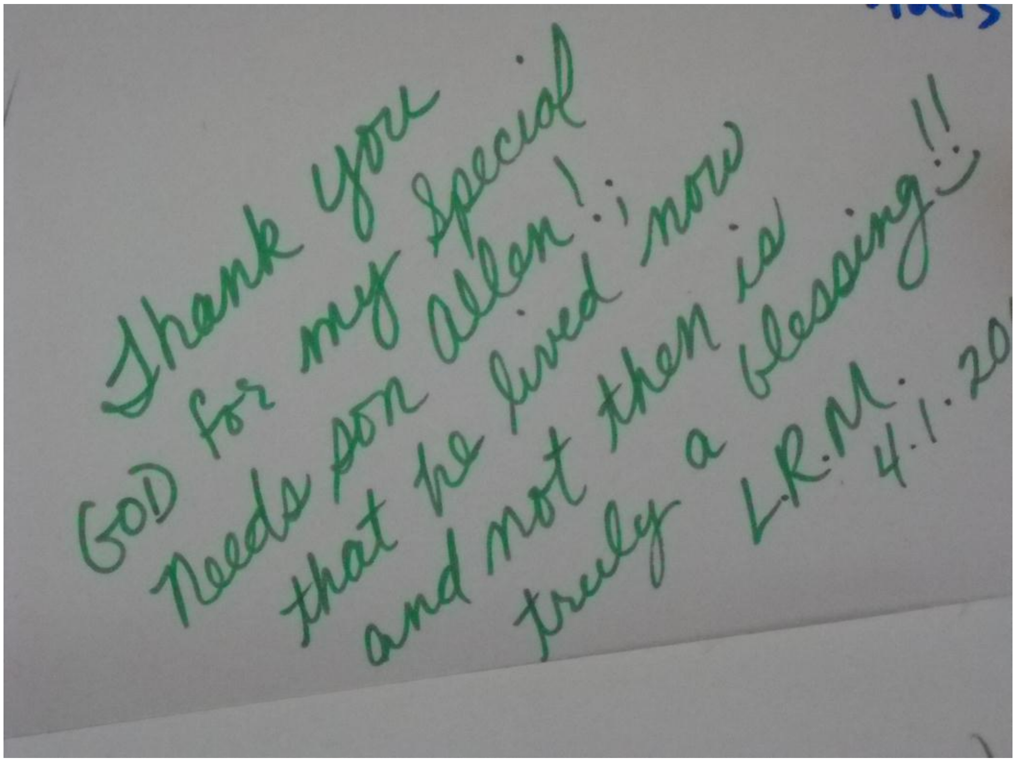


Lord, bless all the people in the past who made it hard for your Angels on Earth, for they knew not what they were doing. Thank you father for making it better as time went on. Amen

- Cindi M. McDaniel
4-1-11

Tara Pastor
Zontaye Richardson
- Liberty Center -
Bright group

Figure 5.1 A comment in the form of a prayer



Thank you GOD for my Special Needs son Allen! now that he lived and not then is truly a blessing!! :)
L.R.M.
4.1.20

Figure 5.1 A comment in the form of a prayer

A viewer and former human services professional, Pam Long commented on the art pad at the exhibit as follows: “Montgomery County, may you be strengthened to accept and enjoy the gifts of those living in our community. How blessed we are to be one with them.” After Pam’s signature, someone wrote in a different color, “Amen.” I later spoke with Pam Long, who is a Christian Education director for the Archdiocese of Cincinnati. I recognized her name; she had been a public relations specialist for developmental disabilities at one time. Pam believes that fear of people with developmental disabilities is rooted in not being in touch with one’s full humanity. She used the Latin term *veritate*, meaning “charity in truth,” which she relates to authentic human development where “through love, we help to teach people to achieve their full potential.” This spiritually inspired motivation to help and support is noted in other comments.

The theme of social responsibility may be based in humanitarian concerns from religious beliefs. A University of Oregon lecture series on spirituality and human services (http://www.youtube.com/watch?v=D8Miw731FC8) consisted of presentations from different scholars in relation to historical and current perspectives. The lecturer noted that most helping professions have roots in religion, within the notion of service. I recall a poignant point made in the series: service providers should “drop the story,” meaning they should get to know the person, not rely on a preconceived notion of who they are serving, and see people with disabilities as a group of individuals who are full and equally deserving of a good quality of life, even though they may need assistance. Paired with the philosophy reflected in the Ohio State University’s Disability Studies program, indications are that the next evolutionary step in approaching services is to view disabilities in a different paradigm, one which cultivates respect rather than pity.

"Change" and "resistance" are themes that recurred in the comments and interview feedback. The question "Do people change their minds?" came up in data collection in comments and interviews. The debate about an attitude change is in reference to accepting people who are different, especially through living and associating closely with those people who are different, when they formerly did not do so (See Figures 34 and 35). Howard Gardner (2006, p.124) has listed seven factors that could prompt a change of mind:

- Reason
- Research
- Resonance
- Representational redescriptions
- Resources and Rewards
- Resistances

Gardner (2006) contends that people learn in many different ways. In his seven factors for mind change, he identifies "representational redescription" as the most important way. This is due to the agility of representation, with its varied forms, for example, narrative, drama, or visual art. The point Gardner is making recognizes that people are more likely to learn, and expand their minds, if the information is presented in several different formats. Flexibility and imagination in presentation offer more people the opportunity to learn because people learn by different styles.

“Resistance” is the last factor In Gardner’s list. He informs us that our minds are usually more easily changed when we are young. When we are older, our minds are set. Therefore, when an event occurs that one is opposed to, such as people who are different moving in next door, resistance may initially be manifest in the neighborhood. Yet, new experiences may present teaching moments, for instance, a direct encounter with someone with disabilities. This is when experience can make an impression and potentially change minds.

Educating the public about people with disabilities removes some of the mystery and allays the provocation of fear-based resistance. The installation presented information in a safe, non-threatening way, and viewing of the exhibit was optional. This is not the case when people with disabilities move in next door and one is immersed in the experience. So, the responses of compassion and acceptance were expressed in a safe venue. An unknown person or new “type” of person entering the neighborhood can be perceived as a threat to one’s sense of comfort with where one lives. The meaning of one’s home is very personal. But if the “threat” were a *known*, the fear and discomfort would, theoretically, subside.

Comments from the viewers of the exhibit about change are pictured in Figures 5.3 and 5.5. The comments represent two differing viewpoints about change. They show how some people welcome diversity; others resist the world changing to, perhaps, having to share the environs with people who are not of the same color, religion, politics, or values.

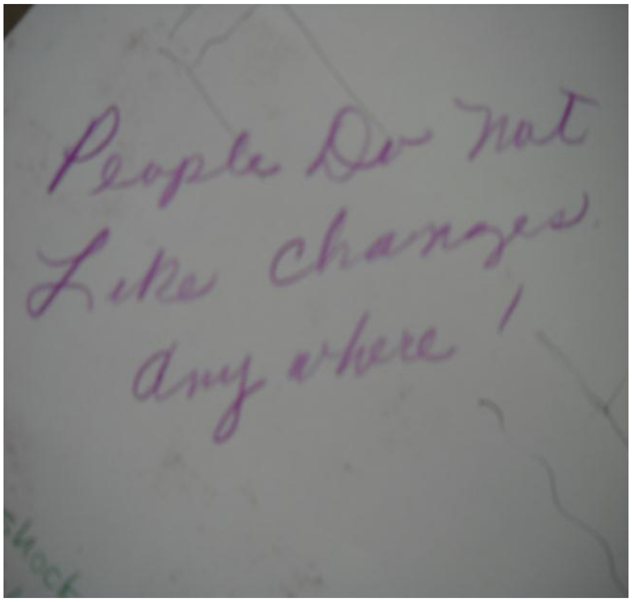


Figure 5.3 Comment on change

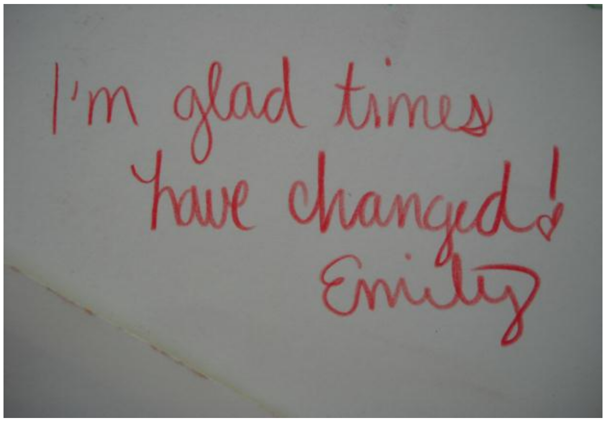


Figure 5.4 Comment on change

I surmised that the comments appeared because the homes that we provide for people with disabilities are perceived of as a change to the neighborhood. The fact that a typical family may not live next door presents a change to the use of the house. The rotation of caregivers brings a variety of vehicles to the driveway, and some on-street parking can occur in front of the property. These are barely noticeable changes to the neighborhood as a whole and hardly rate the uproar that is generated when resistance movements form in opposition to the prospective development of a rental property for four people with disabilities. As it turns out, if the properties are maintained with quality maintenance and concern for appearance, there is little impact on the neighborhood. But, as revealed in the feedback from some people, change is difficult to accept.

Analysis of the Interviews

As a technique of mining for deeper understanding, interviews promise to provide very interesting data. The viewer/participants that I interviewed shared feelings about their convictions. The experience of interviewing revealed to me the passion with which people speak about advocacy and, again, the themes of change and resistance.

The interview format was one of open-ended questions asked by the researcher, which allowed for conversation. Holloway (2006) recommends that, during an interview, the researcher should be aware of how one makes meaning: “Through a filter, go in with an openness and allow articulation of layers of talk so that meaning, knowledge and perspective came out of talking” (Holloway, 2006).

I selected the five individuals to interview based on their apparent interest in my project, and the different angles with which they approached the issue. They came from different perspectives, and the interview responses unfolded in varying ways. 1) Teresa showed such passion when she saw the exhibit that she hugged me. Remarkably, I had not met her before the day she happened by. Her willingness to do the interview was shown by her immediate “yes,” and her input was thoughtful, though she had no direct experience with people with disabilities. 2) Steve and Nancy Huff, who made time for an interview with me on a rainy Friday night after they had put their four children to bed, carefully considered their feelings and attitudes toward the tenants with disabilities in a house next door to them. 3) Shirley, from another neighborhood, shared with me that she was perplexed as to why taxpayers need to provide for people with developmental disabilities, and why the house we provide for four men needs to be located two doors down from her home. In spite of being opposed, she spent much time with me, sharing her concerns. 4) Latisha wanted to be a part of this project, from its inception. She allowed me to bounce ideas around with her months before creating the exhibit, then viewed the product and later granted an interview. She is very appreciative for what she has been given, having suffered from poor treatment in the first two decades of her young life. The quintessential advocate, Latisha is a recipient of services and voice of the group about which I presented. The exhibit moved her to identify with the individuals that had been institutionalized, even though she had been born in a later era and has had different experiences. 5) Mark, a top-tier administrator, provided me with affirmation that the installation did, indeed, communicate the conditions of life in institutions, but he also reminded me that the civil rights movement is ongoing. He revealed his continued commitment and compassion, and said that people are just people, and anything we can do to present actual people with disabilities will dispel the myths. People learn by individual examples. In his leadership position, Mark is in touch with individuals but can also see "the big picture."

Similar themes from the interviews emerged that are reflected in the verbal responses. For example, as in the comments on paper, a theme that also emerged in the interviews is that of spirituality. The first time Teresa saw the exhibit she hugged me and said, "Bless you!" She returned that afternoon to show me the passage from a daily inspirational book regarding caring for others. The Huff couple shared with me how their Christian faith promotes giving to others and that they are pleased to support the women who have developmental disabilities living next door. Latisha said, "Thank God for the people who take care of people like me," exuding her gratitude in a spiritual statement. Mark had shared that he had trained for the seminary, but found that direct work in this field of social services was more his calling. Shirley, resistant neighbor, did not make direct reference to a spiritual sense, but did share her sense of neighborly concern in helping the men with developmental disabilities in her neighborhood after the hurricane. Even though she is not fully accepting of the use of the home two doors down from hers, she gave of herself for the welfare of her neighbors—a humanitarian gesture which could be classified as a sense of societal responsibility.

Another theme that recurs in four of the five of interviews is societal responsibility for how people with disabilities in the past and in the present have been treated. A form of collective guilt was palpable during the four interviews in which this theme appeared. In the words of Teresa Susberry, one of the viewers who commented, “We are our brother’s keeper.” Yet, she recalled making fun of the mental institution on the hill in her neighborhood, as did the other children in her neighborhood, sharing that this demonstrated ignorance about people with disabilities. Mark Gerhardstein discussed the deplorable conditions in institutions with dramatic disgust, communicating a message of shame on society. The Huffs seemingly constant concern was for the population of individuals who were not capable of independence. Nancy Huff mentioned her aunt who began a program in Kentucky in which Nancy had a special interest. Latisha Martin shared her disappointment in her own family’s lack of caring and now is an advocate of people with developmental disabilities. Shirley was the exception in her interview. She repeatedly questioned why taxpayers had to bear the burden of caring for people with disabilities. Clearly, this is her concern about social responsibility, although she has an attitude that may not promote the cause.

The issues of *resistance* and *change* also recurred in the interviews. The first interviewee, Teresa, shared that she understood resistance from her example of not having really known the individuals in the institution on the hill: “Like many others, I was ignorant to the true facts associated with many aspects involving disabilities,” she stated, ”I am now able to correct the stereotype messages that I was exposed to at an early age, by educating myself.” The Huffs shared how they believe that actual contact with a person with disabilities is key—maybe necessary—to understanding and acceptance. However, they mentioned that they might be somewhat exceptional in their efforts to go out of their way to include different types of people in their family life in order to educate their children. Nancy Huff actually stated that she wished there were more opportunities for their children to be with the women next door. Latisha, as mentioned, advocates for the rights of people with disabilities, as she shared having experienced nonacceptance. She shared disappointment when no one from the neighborhood showed up for the home’s open house. Mark was very proud of his work in zoning reform in the local community, having shared stories of resistance to the location of supported living homes in neighborhoods. Shirley spoke of the public hearing that occurred in the development of the home in her neighborhood, recalling the testimony of people who were resisting the request for a conditional permit by Miami Valley In-Ovations. She indicated having sympathy for the people next to the home where four men with developmental disabilities live, and having concern for their property values.

Another emergent theme was how the viewers who were interviewed reflected on the *quality of life* for the individuals with developmental disabilities. Each person addressed my questions thoughtfully from the perspective of their own lives. For example, Latisha is a self-advocate. She stated that her family does not understand how she wishes to live. She is too young for having been placed in an institution. But she saw the model of the state institution ward and she said that it made her glad she had not been born earlier. She thought it was, in her words, "really dark and hard." The sympathetic neighbors had shared that what they saw depicted in my exhibit evoked a stark example of neglect. As people who accept that the four women next door to them deserve as nice a house as they have, this couple has indicated that quality of life is partly where one lives. Teresa saw the elements of the exhibit as a reminder of how a relative kept her son inside his home so he was never integrated with others, which she felt was very wrong. Mark, the administrator, indicated a strong advocacy for equal rights to a quality of life for all citizens, regardless of ability. He saw the evolution of increased opportunities for people with disabilities depicted in the exhibit as accurate but wished to relay that this civil rights movement is not ended.

Even given a small sampling, the recurring themes indicated that the challenge of integration in a community is multifactored. The interviews revealed that motivation for the acceptance of people with disabilities in one's immediate world may be from a spiritually based intent, or one of having witnessed the population. The conceptual pendulum swing of society's approach to the problem—from isolation to integration—may also account for increased acceptance.

As a technique, interviewing involved the participation of viewers and produced rich results about people's thoughts. The five people interviewed represented a passerby, a primary recipient of services, two examples of neighbors, and an administrator. The number of those interviewed could have been larger, although my sample was representative of a variety of perspectives. My research may have benefited from more data gathered from interviewing other people: staff, for instance, or a direct stakeholder such as a parent of a person living in a supported living setting. The sample size considered, however, five or fifteen interviews may have resulted in similar results.

Analysis of the Effectiveness of the Methodology

Evaluating the effectiveness of an art installation calls for tailored sets of standards that relate to the mode of inquiry; traditional research tools for evaluation may not fit. Arts based research is evolving, and as such, criteriology and rigor are important considerations. In an article published in *Qualitative Inquiry*, Finley (2003) cites Piantanida, McMahon and Garman: “To gain respect for an arts based research genre, fixed quality criteria needed to be named for evaluating arts-based work.” Finley goes on to point out that “the research community has a bias against the intellectual viability of the arts as the conceptual framework for research” (p. 289). She suggests that scholars who engage in the emerging methodologies create standards reflective of the approach itself, for the very qualities that are provocative in art are the elements we, as arts based researchers, understand to be intrinsic. Atkinson (2010) and Knowles and Cole (2008) consider creative elements in arts based research and the role of the researcher, themselves. Barone and Eisner (2012) set out to establish standards by which arts based researchers may assess the effectiveness of their research. Comparing this research project to these standards shows that the project holds up in its fruition and results.

Atkinson (2010) states that an important consideration in arts based research is to maintain quality in the creative elements of the pieces. Aesthetic features should not be put aside for the sake of communicating a sociological phenomenon. She also calls for felicity in performance. “Felicitous enactments are simultaneously technically accurate, interpretatively sensitive, and produced with the appearance of effortlessness” (p. 72). The installation served to inform, and yet I intentionally wanted to maintain artistic integrity. The exhibit contained the elements of design, composition, and color, as well as technical accuracy and sensitivity. It was not, however, an “art exhibit.” It attracted attention and seemed to communicate the social changes that have occurred and are still needed. It was contained in its space, and had a flow and points of interest, with overall thematic consistency. Evidence of the installation’s integrity as art is indicated in some of the comments and interviews, as well as in compliments that were personally told to me after the installation was dismantled. And, although sensitivity to the officials passing by did, admittedly, cause me to curb a temptation to present more boldly, I believe that I was able to provoke emotions effectively.

Knowles and Cole (2008) list defining elements of arts-informed research, which is useful in analyzing this project. The scholars’ seven criteria are:

1) Involves a commitment to a particular art form
2) Contains methodological integrity
3) Is open to human imagination in the creative inquiry process
4) Presence of the researcher in the artistry and research text
5) Contains strong reflexive elements that evidence the presence and signature of the researcher (not necessarily as subject)
6) Relates to audience beyond academia

7) Is the centrality of audience engagement and “is explicitly tied to moral purposes of social responsibility and epistemological equity.” (p. 62)

Each of Knowles and Cole’s (2008) elements was involved in the project in the research installation. First, the art form—an exhibition containing artistically created displays with mixed media—was chosen to represent the topic in a public forum. Secondly, photographs of figures and faces along with stark symbols of an historical setting served to tell the story. These forms of representation meet with the methodological integrity to best reach the answer to the inquiry regarding the ability to influence attitudes of participant/viewers. Thirdly, I remained open to the project evolving toward best effectiveness for the inquiry. I allowed for a variety of input that I received along the way to influence the product. I allowed the creative process to inform me, through completion. Fourthly, as researcher, my presence was clear both in the art and in the message. However, I allowed reflexivity in the creation of the installation. Fifthly, the process of creating the exhibit—the small conversations surrounding the public showing, the comments on the drawing paper, and the open-ended interviews with the five participants—all contributed to informing the researcher/artist. Also, the people who are audience, participants, were the public. The opportunity was seized for the exhibit to be held in a public place; a chance unfolded for the ideal space at the time of the Developmental Disabilities Awareness Month. This demonstrates the intent to reach an audience outside academia and the disability communities. Lastly, as to audience engagement, the installation was explicitly intended to draw the participant/viewers into the social phenomenon in order to evoke interest and prompt attitudinal shifts. Knowles and Cole indicate that “the research text is intended to involve the reader/audience in an active process of meaning making that is likely to have transformative potential” (p. 62).

In evaluating effectiveness, Eisner (as cited in Bagley and Cancienne, 2001, p. 222) highlights the need for researchers using arts-based approaches to present their data to ensure that they create something that a reader or viewer will find meaningful. During this research project, I considered ways that meaning can be realized, and have formed the following categories:

- Personal – As used in the cathartic and informational effects of journaling or depicting an experience using art. My experience allowed me to gain a deeper understanding that I could not have simply read or heard about.

- Interpersonal – As when interaction occurs between researcher and participant. The exchanges that took place between the viewers and me, during and following the exhibit, were rich with story and identity, allowing for empathic responses on both of our parts.

- Collective – As in a formal or informal group or a local community who learn from reflection about a shared experience. Having identified the group, people with developmental disabilities, one can identify this as the collective. However, all of the participants who connected with the storyline of the exhibit—from creation to reporting—became the collective in this project. There is a sense of sharing that occurred as a result of our experience.

- Cultural – As in research about an ethnographic group. The research, indeed, produced cultural awareness about the ethnographic group, and about people in a society. Social behavior was front and center in this project, as were the comments on how our culture views and deals with people who are different.

In order to analyze the effectiveness of the installation as an arts-inspired research method designed to provoke responses to the history and treatment of people with developmental disabilities, I settled on a new template from Barone and Eisner’s most recent book, *Arts Based Research* (2012). The scholars first discuss why a researcher would choose this methodology. Describing conventional social research as typically approached with the “assumption that all research is meant to bring us closer to a final understanding of various dimensions of the social world,” they go on to state that “using arts based research means abandoning the notion that the research process—whether through social sciences or otherwise—should *always* result in a more persuasive argument, or interpretation of how social and cultural phenomena are best perceived or conceptualized” (p.14). The inquiry was actually about how an arts-informed installation affects viewers, with the particular focus on a weighty social issue. Had I chosen to research the socially significant evolution of services to people with disabilities, I may have used phenomenology, case studies, or critical ethnography. The use of arts based research proved to be an effective method for the intended purpose of generating new information about the public’s attitudinal shifts.

Barone and Eisner (2012) provide six criteria for appraising arts based research: incisiveness, concision, coherence, generativity, social significance, and evocation and illumination (p. 148). Using their criteria for arts based research; I evaluated my research project based on these elements in the definitions by Barone and Eisner, which are in quotations below.

Incisiveness. “The researcher gets to the heart of the social issue. Incisiveness means that the work of research is penetrating; it is sharp in the manner in which it cuts to the core of an issue.” (Barone & Eisner, 2012, p. 148)

The installation was intended to display an historical perspective on an ethnographic group, and to bring to the viewer’s awareness the critical issues involved in housing individuals within this group. The mistreatment of the past was displayed in two- and three-dimensional mediums. This social issue is a civil rights movement, given the resistance witnessed locally and nationally, regarding the acceptance of people who are “different.” There was no doubt what the installation was about.

> **Concision.** The degree in which the work of art occupies the minimum amount of space and uses the least amount of verbiage necessary for it to serve its primary, heuristic purpose of enabling members of an audience to see social phenomena from a fresh perspective. (Barone & Eisner, 2012, p. 148)

The stark scene got to the heart of the issue, viewers reported. People stopped at this small grouping to consider what life must have been like in the days when individuals were warehoused in state institutes for having been born with subaverage intellect or physical deformities. Photos displayed in the large “filmstrip poster” flowed chronologically. Each index card contained historical markers, simply worded so as to be read in a brief period of time by the interested viewer. They were attached at a 45-degree angle so as to appear to be notations from history. One could glance at them, read them, or simply ignore the additional verbiage. Indeed, Barone and Eisner (2012) recommend limited verbiage because many words can “water down” the power of the work, and hence, its effectiveness. I do not believe that the words on the cards detracted from the pictures and symbols meant to inform in an efficient manner. Instead, they served to engage the viewer who chose to connect the objects to historical events. I believe that the exhibit was concise and purposefully presented as a fresh perspective of the social phenomenon.

Coherence. “By coherence, we mean the creation of arts based research whose features hang together as a strong art form” (Barone & Eisner, 2012, pp. 150–151). The elements of the linear piece—which moved from left to right naturally by its invitational vignette, with large pieces at the far left and the tabletop pieces to the right—were situated cohesively. Also, the timeline was linear: the dark and dreary past moved toward the light-filled and colorful home settings of today. The installation seemed to have a beginning, middle, and end. I believe that the piece hung together effectively.

Generativity. “By Generativity, we mean the ways in which the work enables one to see or act upon phenomena even though it represents a kind of case study with *n* of only 1” (Barone & Eisner, 2012, pp. 151–152)

The reference to the representative case study connotes a sample of one, representing one participant. This point helps to describe arts based research as legitimate because the study that has a focus on the experience of one, whether in narrative, drama or work of art, can “shed light on some aspect of the world we had not seen before” (Barone & Eisner, 2012, p. 152).

The installation invited viewers in to see the residential experiences of people with developmental disabilities, both in the past and in the present, and generated thought in terms of a dramatic change. I believe that the comments are the clearest indicator that the exhibit can be described as having generativity. For example, some viewers were moved to share stories that indicated an identity with someone they knew with similar experiences. Comments were also made that revealed a sense of collective guilt for the mistreatment of individuals on the part of past generations. In the interviews, participants shared personal stories of memories that were generated from the exhibit. These connections indicate that the exhibit maintained generativity.

Social significance. *“Social Significance pertains to the character, meaning and import of the central ideas of the work. What makes a work significant is its thematic importance, its focus on the issues that make a sizable difference in the lives of people within a society. What one is looking for is something that matters, ideas that count,*

and important questions to be raised." (Barone & Eisner, 2012, pp. 152–153) They include: "issues of homelessness, of racial divides, of political oppression and the nature of freedom"
(p. 153).

The social significance of the installation was evident: I displayed the ward, pictures, and words marking this social crime, and viewers understood. Symbols of the movement into the community raised issues that society had been ignoring by placing people who are different out of sight. Examples of lawsuits and resulting bills of rights were posted. Newspaper articles, displayed on picture viewers, indicated neighborhoods resisted the move to the community. This has been an issue since the 1970's and remains a challenge. The social significance of the installation was unquestionably evident.

Evocation and illumination. "It is because it is through evocation and illumination that one begins to feel the meanings that the work is to help its readers grasp… Readers are people who secure meaning in whatever form it needs to be read. Paintings are read, music is read, and dance is read. Evocation is therefore an epistemological means for the acquisition of meaning" (Barone & Eisner, 2012, p. 153). In the art installation, I strived for the combined effect of evocation and illumination, or, as Eisner and Barone explain, "When illumination is combined with the quality of evocation within a vivid experience, the work will serve both to illuminate cognitively and to prompt the participant to respond emotionally, as well" (p. 153).

The vignette was evocative; the pictures and words informed and illuminated the issues. Eisner and Barone (2012) state that "evocation pertains to feeling" (p. 154). Many comments revealed that feelings were evoked by the exhibit; I passionately hope that the residual effect of having initiated thinking along with the feelings moved the participant/viewers to consider changing their attitudes, however slightly, toward increased acceptance.

The display of individuals' artworks that showed what home meant to them prompted some drawings of viewers. When individuals from a local sheltered workshop stopped by, they drew pictures of their homes, indicating their understanding of the display. None of these individuals had lived in an institution, but they used art to express their feelings about their homes. The viewing of the homes drawn by the We Care Arts clients evoked this creative expression. One could extend this participation further, by providing more space and mediums with which to create a work that relays a feeling prompted by the artistic installation and/or the messages meant to be communicated. Such activity is a result of art created, displayed, or performed for social change. The beginning of social change is the internalization of the intended message; the next step is the expression of its effect. Repeating an adage using the biblical term “beget,” in the effort to change attitudes through expressive means, I would venture to say that creativity begets creativity.

The Exhibit as an Artistic Medium for Social Change

Exploring the use of art for social change inspired my method of research. Prompted by the purpose—the need for community acceptance—I reviewed examples from artists and scholars such as Rosler (1991), and Crutchfield and Epstein (2000), who understand that art that draws the viewers' attentions needs to be provocative. The presentation in the form of an exhibit evidently caused increased awareness, as demonstrated by the viewers in verbal responses and written comments. As Ellen Dissanayake (1988) passionately observed that beauty causes a shift in the viewer, disturbing images, in turn, can provoke an awareness of a new phenomenon, or substantiate a belief. Likewise, Elaine Scarry (2001) stated that through art “the perceiver, the beholder, gathers power and thus can become the pursuer of justice, armed with the peace that beauty and symmetry bring” (p. 17). Scarry evokes the viewer to become an activist, having been somehow changed. I have witnessed many viewers, however imperceptibly, experiencing a change in attitude after having seen the pieces that I present. The neighbor who was previously resistant to a home in her neighborhood expressed in an interview her concern for the men living near her. Other viewer/participants responded by sharing that they were informed as well as reassured that conditions have improved for people with disabilities.

As mentioned previously, Martha Rosler’s artistic projects for homelessness awareness in New York City were staged in public forums in order to promote awareness and change. I was impressed by the blend of creativity and social commentary that Rosler put forth to prompt attitudinal shifts. I therefore took advantage of the opportunity to not only exhibit my provocative history lesson in public, but also in a government building, thereby hoping to influence policy. Like Rosler, however, I have come to the realization that the most effective messages come from the stakeholders themselves—in her arena, the people who are homeless or in poverty and are threatened by gentrification. In the case of this research topic, people with disabilities are the best representatives of their needs and desires for an improved quality of life. Facilitating their artistic works to influence social change would be a next step in this effort.

Additional Analysis

Considering, in hindsight, different approaches to the inquiry is a curious process. For instance, as an option, alternative research tools could have been used to collect more data to produce meaning. For example, the concept of conducting a survey was presented at the outset of the research; however, the dissertation committee agreed that interviewing would be a much better way of mining for personal response. Surveys may have been inappropriate for an art installation designed to evoke thoughts and feelings, and influence attitudes.

A different setting with more flexible hours might have produced interesting results. What might an installation evoke if held in the lobby of a theater, for instance? Or, if the venue had been in a shopping mall, the results may have been even broader if the public was more widely represented. Were it held in a museum, artificial lighting would likely have been required. The natural lighting in the space was, as mentioned prior, inviting. The lighting maximized the display of the ward and the “filmstrip” timeline.

When present at the exhibit, I was provided the opportunity to note facial expressions as well as hear verbal input. I also gauged interest by observing viewers. However, this availability had advantages that I did not have when phrases or sentences were written while I was not present. McNiff (1998) notes that “it may not be possible to transfer what we experience and know within the framework of painting to a verbal or spoken text” (p. 44). So, although the participation of viewers was documented in written comments and verbal statements that I recorded in field notes, McNiff’s point is well taken: if participants had expressed their responses in drawings, it perhaps would have provided me with a deeper, more visceral form of expression. The few drawings were by people with developmental disabilities depicting their homes in line drawings of houses. Even without artful comments, the many poignant comments from viewers served to extend the story of the exhibit, such as in the case of the mother commenting on the opportunities for her son in the school system.

As the responses reveal, viewer/participants either identified with the stories depicted or revealed feeling compassion for the experiences of those featured in the exhibit. It is evidenced that the research was conducted with an appropriate method and the resulting data has shown success in meeting scholarly criteria for the methodology, and that this research met the desired goals: to present an artful installation that attracts attention of public viewers, and to prompt the viewer/participants to be moved to think, ponder, and comment about the social issue that I have put before them in an effort to influence attitudinal change. In Chapter 6, I discuss the implications of this research project.

Chapter VI: Discussion

In this chapter, I present a discussion related to the experience of the research project, share my own responses in correlation to scholarly references, and summarize the implications of this doctoral research project. Also, I recommend further research that would enhance the body of knowledge regarding this ethnographic group and I consider future research in the developmental disabilities field that would utilize alternative methods of inquiry.

The research conducted for this doctoral study about people with developmental disabilities and their history, with a focus on community acceptance, was my first project using arts based research methodology. The research question was: Can attitudes toward people with developmental disabilities be influenced through viewing an arts-inspired installation?

I believe that this approach was the most provocative means of gathering data from participants, which, in this case, were the viewers. Additionally, I thought that this technique would provide me with an opportunity to become immersed in the culture of the ethnographic group. McNiff (1998) describes the arts process used for research:

> There are ways of investigating the “magic” of creation within the scholarly tradition of aesthetics which speaks of a process of being “seized” by a sublime experience, an insight, or a turning point in expression. The creative process enhances the human experience and the arts can evoke understanding of oneself and inform others. (p. 43)

My research project informed viewer/participants, as well as the researcher, and piqued my curiosity regarding many issues, one of which is the sociological phenomenon of why marginalized groups are treated so inequitably in a society that purports to value humanity. I wonder about how people form humanitarian moral codes, as this research revealed religious frameworks to have been the source of many viewers' expressed concerns.

Beginning with research into the treatment of people with disabilities, I noted historical trends and landmarks from the 1800's until the present, a very long period in American history to maintain the oppression of a people who, in many cases, cannot speak for themselves. My knowledge of how and why our society chose to deal with people who are different has grown, but more importantly, my sense of understanding humanity has been deepened as the viewer/participants responded with such committed comments. Geertz (1973) points out that "a thick description of a human behavior is one that explains not just the behavior, but its context as well, such that the behavior becomes meaningful to an outsider" (p. 5).

Attention to the matter of the disability community as a civil rights movement is long overdue. As Crutchfield and Epstein wrote in 2000:

> While disability has gained public and academic attention from the after effects of the Americans with Disabilities Act, questions of disability representation, access and identity remain. This area of inquiry constitutes the "undiscovered" territory of the late twentieth century. We write "undiscovered" with a note of irony, since these questions have been broached by disabled people since the beginning of time. (p. 3)

The research topic is evidently of a growing contemporary interest because the World Health Organization, jointly with the World Bank, have published recent research regarding a global need for change regarding the care of people with disabilities in general. Journalist David Brown (2011) of the *Washington Post* reports:

> About 15 percent of the world's population—some 785 million people—has a significant physical or mental disability, including about 5 percent of children, according to a new report prepared jointly by the World Health Organization and the World Bank.

> The report, released Thursday at the United Nations in New York, found that the problems are worsened by poverty and dozens of other variables, including stigma, architectural barriers, lack of legal protection, the cost of devices and assistance, and the lack of knowledge by others (especially health professionals) about how to interact with disabled people.
>
> "The message is that we cannot continue to discriminate against or ignore the needs of such a large proportion of the world's population," said Etienne Krug, the Belgian physician and epidemiologist at WHO, who led the study. (p. 1)

The discrimination and barriers that the report highlights still exist in the United States today. No country, of which I am aware, has "arrived" with full assimilation of people with disabilities. But studies such as mine, and others in the growing field of disability studies, provide the first steps in finding ways to help the public fully accept and provide for people who belong.

The experience of conducting this research—creating the exhibition, observing viewers, noting responses, and reporting on the findings—has been very meaningful and definitely transformative for me. I have been able to listen to viewers whose reaction is from their own personal perspective. I realize that how people perceive other people is contextual, individualized, and personal, and I was privileged to hear so many rich stories, as people disclosed their personal experiences.

I took note that people who are moved to express concern for others, even though the topic was not concerning their own family or their vocation, are sometimes motivated by religious values. Social values come from many arenas, such as parental influence and schools. John Dewey, a scholar in progressive education, suggested "children should have the opportunity to learn and practice those skills that are required by a participatory democracy" (as cited in Lee & Fouts, 2005, p. 62). But Dewey also believed in continuing education. As Dewey (1944) wrote, "Real education comes after we leave school and there is no reason why it should stop before death" (p. 25). Wergin (2011) notes that "democratic societies, with their individual freedoms, need education to develop social consciousness, and social consciousness, in turn, is committed to growth and development" (p. 122). The viewers who noted their concerns for the oppression of people with disabilities display their learned values with reflective thought for the common good.

I approached this project from the standpoint of inquiry and frustration from intolerance and resistance. I wondered, what is it going to take to gain acceptance of people with developmental disabilities in the public, with no resistance and no offensive language or behavior? Honestly, I wanted to ask the question, can minds be changed? Howard Gardner (2006) addresses that very question in his book *Changing Minds: The Art and Science of Changing Our Own and Other People's Minds*. He does believe that minds can change, but it may take an incident that is personal and significant, especially for an older person. Gardner indicates that *variety* in presentation of a topic would ideally reach the most people, because people learn in different ways. "There are many effective formats, and the sought-after tipping point is most likely to be reached if a teacher uses several formats flexibly and imaginatively" (p. 141). Gardner lists one approach in education, "representational redescription," as "probably one of the most important ways of changing minds of students" (p. 140). One of the viewers of my exhibit commented on the need for more variety in teaching students who have developmental disabilities because of their different learning styles. I observed that this is true of the general public.

Inspired by a little book by Martha Rosler (1991), an installation artist in New York City who creates “uncomfortable art,” having been moved by the exhibits at the Museum of Tolerance, and having read about the examples of art for social change, I delved into the art based research project with passion mixed with humility. I wanted to make people aware of a certain phenomenology through the art installation. Knowles and Cole (2008) substantiate my motives:

> Consistent with the broad agenda of social science research to improve the human condition, arts-informed research has a clear intellectual purpose and moral purpose. Ultimately, the research must stand for something. Arts-informed research represents, then, art not intended as titillations but as opportunities for transformation, revelation, or some other intellectual or moral shift. (p. 66)

Concerned with diplomacy as a government employee, I made the bold step to hold the exhibit in a governmental building. Had it not been held there, I believe that I could have presented it in a more radical way. Barone and Eisner (2012) address a certain social perspective and the ways art and art based research can shake up the basic way of thinking about a social structure, the ”master narrative”:

> One important attribute of works of art, and arts based research, can be their capacity for enhancing alternative meanings that adhere to social phenomena, thereby undercutting the authority of the master narrative. This may make art appear inconvenient or even dangerous to those who have become familiar and comfortable with the prevailing, dominant, exclusive worldview legitimated within the metanarrative that a work of art or arts based research may serve to question. (p. 124)

Through feedback regarding *resistance*, I gained affirmation that resistance has its root in fear. “Different” takes people out of their comfort zone. I am often told that change is at the root of the resistance in neighborhoods to a different use of a single-family house. The Huffs told me this in an interview. They were hoping that another family would move in next door, perhaps with children that their children can play with.

Homeowners are also preferred to renters, even if the renter does not have disabilities. But I believe that the prospect of sharing neighborly exchanges with people who have disabilities is the first step in breaking down the resistance.

In conducting this research, I experienced *empathy* by being informed by the work of producing the art installation. Bresler (as cited in Knowles and Cole, 2008) notes that "empathy is dialogic…in that dialogue, the researcher/performer is touched and expanded, not just in terms of factual knowledge, but also in her resonance to the world" (p. 197).

My observations, comments on the pad of paper at the exhibit, and interviews reflected true concern about the historical treatment and challenges of resistance today. I observed that viewers of the exhibit have an interest in people with developmental disabilities and how the affected group, as individuals, have lived. Many did not know that there still exists a problem of acceptance. It appeared that viewers were moved to consider how the unwelcome reaction of neighbors affects individuals who will call their new houses "home."

Using the response techniques of written and spoken feedback in the form of small conversations and interviews, I collected data that showed that viewers, indeed, had gained an increased understanding of the problems, due to my having researched and displayed the history of the oppressed group. I have substantial evidence that people were attracted to the installation and learned from its provocative presentation as well as the informative display that was presented in an organized flow. These curious viewers seemed to have pondered the matter of a history of oppression of people with developmental disabilities, as many were moved to express feelings of sadness, empathy, and optimism about change. Viewers became participants by seeing the installation. They disclosed that they were influenced by the artful display, in spoken and written words that included personalized viewpoints and stories.

Implications for Future Research

Arts based research, as a means of inquiry, provides a perfect venue for this ethnographic group to find voice. I believe that increased participation of people with developmental disabilities would provide a means for them to tell their true story. In doing so, they stand to learn about themselves and provide the viewing public with sensitizing information. Drama, music, film, narrative, and fine arts are all mediums which need to be made accessible for more people with developmental disabilities. Techniques such as Photovoice (Wang, 1999) offer a rich opportunity in research, because they inform the creator, participants, and viewers, alike. Another approach to awareness provoking research that involves key participants is participatory action community arts is cited in Knowles and Cole (2008): Deborah Barndt discusses Community Art, which has evolved in various parts of the world over time:

> When people are given the opportunity to tell their own stories—whether through oral traditions, theatre, visual arts, music, or other media—they bring their bodies, minds, and spirits into a process of communicating and sharing their experiences; they affirm their lives as sources of knowledge and they stimulate each other in a synergistic process of collective knowledge production (Barndt as cited in Knowles & Cole, p. 354).

This project also prompted me to inquire about the future of leadership in developmental disabilities services, as the field evolves. As the professionals who witnessed the brutal living conditions of the past retire, younger professionals are hired to assume leadership roles. I am curious about new leaders knowing, firsthand, the legacy of the civil rights movement in developmental disabilities, what will sustain a leader as the field evolves? Will the field be populated with people with disabilities in professional roles, as their voices become louder and true assimilation occurs? And what significant research results can arts based research methods bring to our culture, to help people to realize that people with different abilities contribute to creating a richer experience for all? These and other questions are presented as areas of inquiry for additional scholarly pursuit. I intend to be a vital part of this fascinating quest for information that could improve the social standing of individuals who have “different” abilities and many, as yet unknown, possibilities.

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