

How has the Disability Rights Movement Progressed since the Olmstead Decision?

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Senior Seminar

Abstract

The inclusion of people with severe intellectual and physical disabilities into communities and mainstream society in the USA has been a social problem since the beginning of the disability rights movement in the 1960's. Helping disabled people live independently as part of the community is at the heart of this issue. The Olmstead Decision (1999) was supposed to deter states from institutionalising the disabled and create a culture that is supportive of the disabled within communities. This research examines the progress that has been made since the Olmstead Decision, by the government and the Disability Rights Movement. Using Mount Vernon Ohio as a setting to analyze the kinds of changes that have occurred, the point of this project is to examine the relative success of the implementation of the Olmstead Decision and the success of the Disability Rights Movement.

“The independent living philosophy was born in the disability rights movement. Three essential premises provide the scaffolding for independent living philosophy: (1) each individual is different and unique; (2) people with disabilities are the most knowledgeable experts about their own needs and issues; and (3) programs serving disabled people should be designed to serve all disability groups. The first premise reminds us that each person with a disability, like each person without a disability is unique and should not be labeled or categorized by that disability. The second premise recognizes and promotes the empowerment and self-determination of people with disabilities, and encourages peer support and consumer control of services. The third premise has led to the concept of cross-disability. Given that all people with disabilities are oppressed, independent living programs need to be designed to empower and serve all people regardless of types of disabilities and ensure equal social, cultural, economic, and political opportunities for all” (Hayashi 2007).

The United States is one of the richest and most influential countries in the world; it has an impressive amount of resources and an ability to enact change on its shortcomings. One of these shortcomings is disability rights. People with severe intellectual and physical disabilities still remain outsiders to America’s institutions and any help they receive is seen as a form of charity that they have been given rather than as a right. For this project, I am going to be examining the effects that the Olmstead Decision (1999) has had on the severely disabled community throughout America in the ten years since the decision occurred.

My thesis question for this project is: “has the disabilities rights movement been successful in the decade since the Olmstead Decision for the severely disabled?” The Olmstead decision was a Supreme Court ruling in Georgia that upheld section 2 of the Americans with Disabilities Act, which encourages states to promote independent living for mentally challenged patients instead of institutionalised care (Hayashi 2007:39). Institutionalised care refers to living in a mental hospital where the patient is only

allowed to leave for special circumstances. Section 2 protects the patient's right against being institutionalised against their own will. Section 2 reads,

States are required to place persons with mental disabilities in community settings rather than in institutions when the State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities. (People with disabilities -- Legal status, laws, etc. -- United States. Washington DC:)

Prior to this ruling, section 2 had been ignored and many people with disabilities were being forced into institutionalised care against their own will. This ruling was supposed to force states to use institutionalisation as a last case scenario, and encourage making the community an accessible place for people with disabilities. Through lobbying and a strong participant based social movement, the Disability Rights Movement was able to enact change in the shape of the Olmstead Decision.

While less well known, the Disability Rights Movement began in the 1960's around the same time as the women's rights movement and the civil rights movement. Similar to women and African Americans in America, disabled people have faced discrimination such as being denied equal rights, opportunities, and considerations for occupations, education, and acceptance into main stream society (Lord 2007). Society found it easier to segregate people with disabilities rather than incorporate them into society. Examples of this can be found in the lack of accessibility for disabled people in many of American society's institutions (neither Mather nor McBride are handicap accessible). In many colleges they can only live in special dorms that are deemed handicap accessible. Many voting booths in past elections were not handicap accessible as they were located on the second or third floors of buildings without elevators. The

notion of looking at the disabled's needs as charity rather than rights, was enforced in 1977 by President Nixon.

Although President Nixon had signed the Rehabilitation Act of 1973, and Section 504 prohibited organisations that receive federal funds from discriminating against people on the basis of disability, the Department of Health Education and Welfare refused to issue regulations to implement the law, expressing concerns about costs and administrative annoyance (Hayashi 2007).

Similar to the civil and womens rights movement, one sees similar techniques used to advocate for their movement and to enact change. The disability rights movement responded strongly to Nixon's lack of support, by staging a 25 day sit-in that year in federal buildings in San Francisco (Hayashi 2007). The disability rights movement found support from other oppressed groups as they were brought food by the Black and Gray Panthers. This act of non-violent protest was successful; the result was Secretary Calvano signing off on regulations to give disability rights groups the funding they would need to implement the act of 1973 (Hayashi 2007). This act is highly regarded as the "precursor of the Americans with Disabilities Act (ADA)" (Hayashi 2007). The ADA (1990) is widely seen as the most important piece of legislation passed. The ADA is made up of five different acts regarding the equal rights and treatment of persons with disabilities. Act I applies to employment opportunities, Act II to public entities, Act III to public accomodations (commercial facilities), Act IV to telecommunications, and Act V is made up of miscellaneous provisions. The Olmstead decision which I am specifically examining, stems directly from the ADA, section 2 regarding independent living (<http://www.ada.gov/>). The issue at the heart of all of these pieces of legislation is the idea of assisted independent living. The government has shown an unwillingness to help incorporate the disabled into mainstream society; it would rather place them in segregated

mental hospitals, where they live separated from the communities they were born into. The Olmstead decision was supposed to result in the enforcement of the idea of assisted independent living for the disabled. Prior to this decision there were many cases of people of disabilities (mainly persons with downs syndrome) being held in nursing home facilities against their own will, when they had been cleared to live independently with assistance (<http://www.bazelon.org/issues/disabilityrights/incourt/olmstead/index.htm>). In this project I am examining the implementation of the Olmstead decision and its progress in the ten years since the decision was made. This project also examines the past history of the Disability Rights Movement in order to assess what kind of future progress the movement might have.

The assessment of the Olmstead Decision and the success of the Disability Rights Movement is especially interesting for me. For two years at Kenyon, I have helped run a program working with a group of twenty intellectually and physically disabled students (ages 18-22) from the nearby high school in Mount Vernon. For 2-3 hours a week, these students come to Kenyon and hang out in our athletic center and eat lunch with us. This program mainly serves as a social outlet for these students and helps break up their day from the sometimes-tedious nature of a traditional high school curriculum. These acts and pieces of legislation directly affect many or all of the students in the class, as many of them will look to incorporate themselves as part of the community after they graduate. The idea of inclusion and exclusion is a theme that has become apparent to me while spending time with these students. Being incorporated as part of mainstream society and included in the community means the world to these students, as fighting exclusion has become such a big part of their lives. Inclusion in simple traditions like attending a high

school football game or a school dance are moments of great importance to these students. The physical and intellectual disabilities that many of these students were born with have left them obviously outside normalcy. The idea that the government would rather place these persons into excluded mental facilities rather than help them live in normalcy within their communities is unfair and should be viewed as a violation of human rights.

Literature Review

One way to assess the potential success and implementation of the Olmstead Decision and the Disability Rights Movement is through legal language, and the economic incentive that the state has to implement change. However, one can also look at the potential success of a movement through analyzing the history of the movement and the theory surrounding social movements.

Prior research done in regards to the Disability Rights Movement and the implication of the Olmstead decision gives evidence for both the movement's potential success and failure. This can be largely attributed to how recently the Olmstead decision has occurred and how young the Americans with Disabilities Act is.

The specific language of the Olmstead Decision has left many people skeptical about whether or not the government will make a serious and concerted effort towards funding independent living. Joel Teitelbaum, Taylor Burke, and Sara Rosenbaum, examined the potential progress of the movement and its potential to invoke change (Teitelbaum, Burke, Rosenbaum). Interestingly, the authors find that it is unlikely that the decision will be able to promote change as a result of the semantics of the texts of the Olmstead Decision. The decision requires "public agencies to create reasonable

modifications,”¹ to its current programs but not “fundamental alterations of the programs.”² This is giving states a loophole to get out of putting significant funds towards the ADA; as a result states will most likely be able to get away with giving money that will not support a fundamental change to the current system. It will be interesting to apply this reasoning to assessing the amount of change that has occurred in Mount Vernon, whether they have increased funding significantly enough to create fundamental alterations to the previous system in place.

A similar study by Reiko Hayashi found a mixed set of conclusions about the Olmstead decision’s ability to enact a fundamental change to the current system. Hayashi assesses the cost, benefits, and constraints as well as what the future may hold for the disability rights movement. Hayashi raises the idea that states will be saving money by not institutionalizing the intellectually and physically disabled who do not require it, as it has been found that it is significantly cheaper to not have people in mental institutions full time.

However, Hayashi also finds that funds are higher for people with severe disabilities that may require constant in home care and physical adaptations to make living independently more accessible, such as ramps and elevators. Hayashi, similar to Teitelbaum and Burke, points out the loophole in the Olmstead Decision that gives the states leeway when they say they are required to fund reasonable accommodations. Hayashi gives more support to the notion that states can find loopholes within the Olmstead Decision to avoid giving the necessary funding that would provide people with disabilities convenient independent living.

¹ <http://www.accessiblesociety.org/topics/ada/olmsteadoverview.htm>

² <http://www.accessiblesociety.org/topics/ada/olmsteadoverview.htm>

In contrast to the last article, the article, “approaches to implementing the Olmstead ADA Ruling,” argues that the Olmstead act will be efficient and effective in the short and long-term.³ This study looks to economic reasoning, claiming states can cut cost significantly by putting fewer people in institutionalized care, and that the current recession should only give states additional incentive to do this. This gives a new angle of measuring the potential for success of the act as it would be interesting to see how much money states have saved by not holding certain patients against their will, and how much of that goes back into helping persons with disabilities live within their communities.

David A. Snow and Sarah A. Soule, provide a rubric for analyzing social movements in their book “A Primer on Social Movements.”

Broadly conceived, resources include almost anything that movements, and other organizations, need to mobilize and deploy for the purpose of advancing their interests. This includes, most generally, people and money, and some degree of legitimacy within one or more sets of relevant actors, such as the movement’s constituency or the larger public (Snow and Soule, 2009).

In assessing a social movement such as the Disability Rights Movement, one can predict its potential success by studying resource mobilization theory within social movement theory. Resource mobilization has five different aspects to it. There is material, moral, social-organization, human, and cultural resources. When assessing the Disability Rights Movement within the context of resource mobilization theory, one sees several re occurring themes.

Snow and Soule describe the first category of resources as material. Material resources are made up of five sub groups; money, supplies, physical space, transportation, and employment. The authors say the how the context of the location of the movement

³ “approaches to implementing the Olmstead ADA Ruling,”

and the status of the current economy is directly related to success in material resource. Snow and Soule point out that in times of economic crisis social movements are less likely to progress, because less capital is available to them and to their supporters. Although having the movement centralized in a big city can also help the material category of the movement. The disability rights movement is more or less centralized in Washington D.C., which could help the movement as DC is a major US city with a lot of wealth in it.

The second general resource group is human resources. Human resources refer to the three different kinds of human labor that go into making a social movement operate. These are generalized labor, specialized labor, and leadership. Generalized labor traditionally refers to the less skilled jobs within a movement, often referred to as grunt work. These are the “envelope stuffers, marchers, and picketers” (Snow and Soule 2009: 90). Although these jobs are unskilled, they are vital to a movement’s success as we learned from past movements that this kind of participant activism could be effectively used to create change. The specialized labor consists of the skilled jobs such as “computer experts and legal councils” for example (Snow and Soule. 2009: 91). The third category of labor is leadership; this role can be taken by any of the above listed jobs, as organizational and inspirational leaders are important for a movement’s success and come from all areas of the movement.

The social organizational resource category of social movement is less tangible than the human and material categories. According to Snow and Soule this is the infrastructures, social networks, and formal organizations. This category looks at the different organizational aspects of the movement, as well as the kind of public

representation and backing it has. This can come in a number of forms, as support from other movements, or possibly support within public officials and government, who will help the movement along. We saw an example of this early in the Disability Rights movement when the Gay and Black Panthers supported the sit-in in San Francisco.

The moral category of resources is explained as the legitimacy, solidary support, and celebrity within a social movement. This resource relates to the framing of the movement in the public sphere, and any kind of special support or endorsement the movement might have. An example of this might be an ad campaign run by the movement to create a positive attitude in the public towards the movement. According to the authors an effective way to do this, would be to get a high profile, positively viewed celebrity to endorse the movement. The idea behind this resource is looking at how effectively the movement was able to get the public to support their cause.

Finally the cultural resource is the strategic and tactical approach of the movement described by Snow and Soule as the repertoires and recipes. This is the movements' strategic approach to making progress. This is how effectively the movement is able to strategize with the public as well as in legislation and within the political system.

“While it is arguable that all five general resource types are of some importance to all movements, there can be considerable variation in the relative importance of the different subtypes to different movements” (Snow and Soule 2009: 90). It is important to consider the context and the cause of the movement when examining it within the context of resource mobilization theory. Each of these resources has a different importance depending on the social movement.

When examining a similar movement, the civil rights movement, one saw a strong emphasis on the human, moral, and cultural categories of the movement, while it lacked significant material resource. The civil rights movement effectively used their large and active participant activists, leaders, and group solidarity to create change, through organized sit-ins and marches. Here we see the strategic aspect able to overcome the deficits they had in their economic resources.

The book “social movement and social organization theory” looks at social movements that are largely run and funded through specific organizations. It looks at the organization and the strategy used by these movements to create change within society. This study also examines the role of advocacy within a movement. The disability rights movement does not have a centre or single organizational body; it is up to individual organizations to unite and create a central stance for the entire disability community. Similarly to the study by Foster-Fisherman, Jimenez, Valenti, Kelley (2007), this study also raises questions about the Disability Rights ability to find leadership within their movement, and how effective they can be as a movement without any centralized leadership.

The study by Hank Johnston and John A. Noakes (2005) , is another source that looks at social movements from a fundamental perspective. Johnston and Noakes also compare social movements. One sees a lot of similarities when looking at the Olmstead Decision alongside Brown vs. Board of education decision, as a way of comparing how law and legislation gets put into effect. The authors look at the political side of movements as well as grass roots activism within movements such as protesting, and how it is and is not effective. The first similarity of the movement is the initial ruling, in the

Civil Rights Movement. This was to end segregation and “separate but equal.” However, creating law and implementing it are two different matters. One does not see the implementation in the civil rights movement until after *Brown vs. board of education*. Similar to the Disability Rights Movement, we see the ADA in 1990, and the *Olmstead Decision* in 1999. Here the Disability Rights Movement is attempting to follow the civil rights movement and use the *Olmstead Decision* as a jumping off point to get implementation underway.

Having looked at the previous literature and findings on the Disability Rights Movement and the *Olmstead Decision*, in my research I expect to find that there are several places that the movement needs to improve if it is going to successfully implement change within American society. There is a lack of leadership and unification within the movement; these two themes are directly related, as a group of good leaders could bring unification to the movement. Another issue that is raised is the loophole within the *Olmstead Decision* ruling that does not require the state to give funds to create substantial change to the current system.

METHODS

I evaluated what the disability rights movement has accomplished and what there is left for them to do. Using Mount Vernon as a setting for my research, I looked to understand what noticeable changes have been made to help people with severe disabilities live independently as part of the community. I examined the public facilities in Mount Vernon and see what physical changes have been made to them. In addition, I

interviewed members of the Mount Vernon disability community to see what kind of progress the movement has made.

The methods for examining how the Disability Rights Movement has progressed in the decade since the Olmstead decision consists of two different parts. There was a facility tour of a number of different Mount Vernon public facilities and I conducted interviews.

The tour that was conducted of public facilities in Mount Vernon, included the public high school, city hall, and local transportation. During these examinations of the facilities, I looked for ways that the facilities have been changed and adapted to convenience the disabled. Although the Olmstead Act specifically applies to the helping the intellectually disabled, a lot of the time the intellectually disabled are the mentally retarded and also have serious physical disabilities. As a result, I checked for certain accommodations such as ramps and elevators for accessing the different parts of the facilities. I also saw what kind of people, have been hired to help and direct people with disabilities who come in, whether this be a receptionist, secretary, or an aide. Convenient public transportation systems are also important; I examined what kind of transportation or busses they have that are handicap accessible.

In the second part of the my methods I conducted interviews. This was where I derived the majority of my data that I used to assess the disability rights movement. There were 7 interviews conducted. There were three interviews conducted with disabled students from Mount Vernon High School, who have both physical and intellectual disabilities, who at some point will have to face the predicament of whether they should

live in a mental institution or as part of their community.⁴ There were also two interviews with Lawyers from Washington D.C. who work closely with the disability rights movement and the Olmstead Decision as part of their jobs. And there was an interview with the head teacher and teachers aide from the Mount Vernon special needs class, Transition Mission.

These interviews ranged in questions from about 16-25 based on who the subject is being interviewed. They took somewhere between a half hour and an hour. The subjects were all be provided with a consent form before the interview that explained the nature of my research and explained their rights as an interviewee with me. In these interviews my aim was be to understand how each of these groups of subjects views the Disability Rights Movement, where they see it going, and how they have been personally affected or not affected by the Olmstead Decision. In the selection process of the students with disabilities, I worked closely with the teachers and aides of the students (all of the students are adults over the age of 18) to decide who it would make the most sense to interview, based on their life experiences with disabilities and their functioning levels. I also had the students' teacher present during the interview to ensure the comfort and integrity of my research. During the interviews I took detailed notes on the responses; I did not use a tape recorder. I did not link names with quotes in my research and I assigned pseudonyms in order to keep the confidentiality of the responses. In addition I destroyed the interview data after I used them for my reserach.

For the qualitative data collection for my project I conducted three student interviews of students that all attend the special needs class at Mount Vernon High

⁴ All the people being interviewed during this project will be over the age of 18, and considered legal adults.

School (Transition Mission) and that live within Knox County. Going into these interviews I had no idea what to expect from these students as I have become close friends with them over the past year, but have never had a conversation with them that challenged them to talk about their disabilities. This was particularly difficult for me because I conducted these interviews during the program that I help run once a week. Because of time constraints and limited opportunities due to both my schedule and their busy curriculum this was my only opportunity for the interviews.

This was difficult because a main goal of the program is to eliminate social pressure for the students and to help them feel comfortable socially. As I began to conduct these interviews it was clear that the professionalism required of the interview process and the challenging line of questioning was contrasting everything the program had set out to do. As a result I only conducted three student interviews as I felt that the amount of information that I could stand to gain from additional conversations with the students was not worth potentially alienating them from the program and jeopardizing our relationship as friends.

That being said, I was still able to learn a lot from the three students I talked to. The interviews were conducted at the Kenyon Athletic Center in the main study lounge, with three students of different backgrounds and disabilities. For these interviews I had twenty questions listed that I wanted to address. However, it became clear to me during the first interview that it was not going to be as simple as a question and answer the way I had drawn it up. While explaining the nature of my research and the consent form to the first student (who we will call student A) I noticed the technical language and the professional atmosphere were having a negative effect on the student. The usually

talkative and independent student (Student A has Downs Syndrome) became nervous and began to tense up. This resulted in the student losing confidence in her own abilities and forgetting answers to questions they knew the answers to such as what their age was. I also felt while explaining the nature of my research, Student A may have been made uncomfortable by the fact that my research was in regard to her disability, an extremely personal topic to many of the students that some of them do not feel comfortable addressing.

As a result of the adverse effect of the interview on their comfort level, Student A and I decided to take a fifteen-minute break and then decide if we wanted to continue with the interview later. During the break I convened with the aide who had been present during the interview. She explained to me that a number of different circumstance were probably contributing to the uncomfortable environment, one being her own (the aide's) presence, as well as the large amount of technical and professional language that I had used. We then brainstormed ways that I could receive answers to the questions that I was looking to address without intimidating or making the students feel uncomfortable. During the recess student A and myself met, after apologizing for the overwhelming approach I had taken in my research, we decided to try the interview again in a less formal setting without any teachers present (as the teacher took a back seat about 10 yards away in the room). The second attempt was more successful; I was able to get my questions answered by asking the student questions that led to elicit responses from the student about their own personal life. This was also done without mentioning her own disability, resulting in an easy, comfortable environment for both of us.

This was a valuable learning experience as it showed me the potential adverse effect of my research. My experience with student A also helped me learn an approach to the interview that I was able to use in the other student interviews. Fortunately, I was able to learn this lesson with Student A, who is especially independent and outgoing, and was not too intimidated to try the interview a second time. Had this interview occurred with many of the other students, I fear I would have completely alienated them from my research as well as potentially ruined our friendship. These reasons largely contributed to my halting my disability subject interviews at three as I value my personal relationships with these students far more than the potential data they could provide me with for my project.

Using the experience from my interview with Student A, I was able to approach my interview with Student B much more effectively. This was especially important with Student B, who suffers from a number of different disabilities, among these is an extreme anxiety disorder that Student B deals with by having a black lab with her throughout the course of the day. The presence of the dog and the ability to pet it helps the student calm their nerves and function more effectively. This student is easily scared away and made uncomfortable by social situations; the experience gained from the first interview was crucial to being able to converse with Student B.

I felt that I got all the answers that I needed out of three student interviews. In retrospect it would have been interesting to focus more of my qualitative data on talking to local officials that deal with state funds and the implementation of changes in the town of Mount Vernon.

Transition Mission Background

In examining the changes that have occurred as a result of the ADA and the Olmstead decision, one needs to look no farther than the special needs class Transition Mission which I have worked closely with over the past year and a half and throughout the research process. Created by Nancy Gregg (who was also interviewed), a teacher and the head of the program since she created it in 2003, Transition Mission is a model example of the types of programs that need to be set up and institutionalized as part of our public school system.

Transition Mission is a regional special needs class for Knox County, run out of Mount Vernon High School. Transition Mission is by definition a work/ study program. Nancy Gregg was able to create this program by uniting with the MRDD (Mental Retardation and Developmental Disabilities) and the Mount Vernon career center. The class is made up of 15- 30 (ranging on the year) physically and intellectually disabled students ages 16-22. The ultimate goal of the program is to help the students graduate with the ability to live independently and to have the ability to positively contribute to society. The program tries to challenge each student individually, as some of the more functional students will be set up with a job during part of the day. These students work at restaurants, Good Will, and other locally run establishments in the community as a way to get them work experience for after they graduate. Some of the less functional students will work with aides and teachers at more basic tasks that will ultimately help them live independently. For those this might mean that they help clean the cafeteria after lunch. Although this may be seen as a remedial task or as cheap labor, to them it is a major responsibility that the students take seriously.

Crucial to the success of this program is the strong sense of support within the community that they have. In addition to being involved with Kenyon, Transition Mission has connections and works with students at the Mount Vernon Nazarene University, Head Start, the MRDD, peoples first, day care centers, rehabilitation centers, and a laboratory in town that they use to practice perfecting everyday life skills as part of their vocational learning.

Although this program was not deliberately set up by the government, it would not have been possible to have the kind of funding and support from their own school without the passing of the ADA and the Olmstead decision. According to interviewees, Teacher A and Teacher B, the Knox County school system takes Transition Mission seriously, and has demonstrated their commitment to it through quality funding. The current class of 19 students has one teacher and seven teacher's aides. They have also not received any budget cuts during this time of economic uncertainty. The teachers were also impressed by the school system's support of their innovative and vocational curriculum. Here we see a positive effect of the Olmstead decision, where a change within the community has occurred as a result of participant activism and state funding.

Interviews and Results in Mount Vernon

There were a number of different themes regarding facilities and accessibility for the disabled in Mount Vernon that I was able to take away from these interviews. First there is transportation, activities, both academic and extracurricular, available for these students. Students are transported to and from school everyday by a relatively new service called MOTA (Mid Ohio Transit Authority). MOTA provides all the transportation needs for the students within school hours. This includes transportation to

all student activities, jobs, and to and from home. Outside of school hours students have to rely on social connections for getting transportation. Students participate in out-of-school activities, such as horse back riding, town committees, jobs, and sports teams (special Olympics). However, students must rely on the support of others for transportation for these activities. Students A and B were able to participate in such activities as a result of their family support and connections. However the third student I talked to, Student C, was much more limited in his opportunities outside of school as he is the most functional person in his family of three. He is able to support his family (despite his disability) using MOTA for transportation to his job. He is limited in his extracurricular activities as a result of his family obligations and his lack of parental support in capital and transportation. He is prevented from being able to participate in activities such as horse back riding or recreational sports teams. Teacher A made a point of recognizing that in the current system, “the affluent students with more parental support are noticeably advantaged.” However this raises the question of how different this is from all other aspects of society.

The student and teacher interviews showed progressions of independent living opportunities within the community of Mount Vernon in a number of ways such as the creation of Transition Mission, the availability of extracurricular activities, and the available public transportation for the students to support interests such as jobs and extracurricular activities.

Several of the interview subjects also noted the change in culture surrounding disabilities. Most recently the MRDD changed its name to drop “Mental Retardation” from it. Another notable disability organization, ARC, dropped the “Retarded Citizens”

part of its name as well. One teacher noted that the students are now being recognized as having “disabilities,” rather than being “handicapped,” as the vernacular “handicap” is offensive to the disability community. The teachers have also found a change in attitude of the student body at the high school surrounding the class in the six years of the program’s existence. One teacher noted hesitancy when the program originally started from the student body. Teacher A explained this as being the result of people not interacting with the disability community, as they are segregated from mainstream society, which created a fear of them. Teacher A noted that this hesitancy around the students in the class has almost completely disappeared, as they have become a presence within the school.

Although these changes are all relatively new in Mount Vernon, there is still room for improvement in how often opportunities are available, and to whom they are available. Certain social and class advantages do exist within the current system in place. “The change is slow but steady,” said Teacher A, referring to both the changes in people’s perceptions of disabled as well as the in the structural changes of the current system in Mount Vernon.

Facilities

In addition to the qualitative research for this project, I also took tours of two Mount Vernon Public facilities, the high school and the city hall. The high school is both convenient and accessible for all types of persons. It is outfitted with ramps as well as an elevator, making it maneuverable for wheel chairs. The special needs classroom is located on the second floor of the building by the cafeteria. The program does have classroom accessibility and its own form of transportation. During the interviews with the

teachers and student aides, there was sentiment that their needs are not being completely met.

The curriculum of Transition Mission tries to emphasize the transitioning of students from dependency towards living an independent life in addition to their traditional academic curriculum. The teachers explained that certain life skills could not be taught in ordinary classroom facilities. Certain skills such as cooking and maintaining a living area are necessities to living independently and can only be taught in such arenas as a house like facility. The teachers enforced the idea that such a facility is essential for effectively helping students transition into independence, but that their current facilities favored academic learning. The idea that these students need to take an innovative approach to learning is central to the idea of Transition Mission. The teachers explained that they too are held to certain standards by the school that involve passing a specific state instituted graduation exam called the OGT. The teachers emphasized that learning disciplines such as mathematics, is taught more effectively from an independent living perspective if they are allowed to go out and show students the value of it in the real world. An example of this is learning multiplication through grocery shopping (counting and paying for items), rather than attempting to memorize times tables on flash cards.

Both teachers also noted that ultimately they would like to be able to have two separate classes, as they feel that they cannot affectively challenge students individually in the current system. They emphasized the large contrast from student to student in terms of functioning ability. It seems that there are a group of high functioning disabled students who look to achieve independence, that are being educated with the students who suffer from dementia that makes communication almost impossible and are

functioning on a significantly lower level. The teachers feel that separating the students into two different classes will allow them to educate both groups more effectively. To put this in perspective, in a regular high school class, it would seem inappropriate to expect a student learning pre-algebra to be in the same class as a student learning calculus.

While visiting several facilities in Mount Vernon, I found the public high school is handicap accessible while a number of the older elementary schools in the Mount Vernon system are not accessible for the physically handicapped. In addition to this, the Mount Vernon Nazarene University still has a number of buildings built as recently as the late 1960's that are not accessible for the handicapped. These buildings do not have elevators, and the narrow spacing of the doorways and halls, make it impossible to maneuver in a wheel chair.

While visiting the city hall, I found that the city hall was accessible for all persons. Located in the middle of town, the city hall has ramps, elevators and a number of secretaries and receptionists that are both friendly and helpful, making it easy to maneuver throughout the building and to find what you're looking for.

In terms of public transportation, there is the program MOTA, which you have to schedule ahead of time. There are also two paid taxicab services that operate throughout town. There is no free public transportation during the day or over the weekend that runs scheduled routes throughout the town. Again this revisits the idea that people with physical disabilities with less access to resources are put at a significant disadvantage in terms of accessing the institutions throughout the town.

Group living

Central to my thesis is the question of institutionalised living vs. independent living. In the interviews with the teachers and the lawyers, a main point of focus that was brought up, was the kind of independent living a person with disabilities looks for. There are three kinds of independent living all with positive and negative attributes. First, there is independent living within one's own family. Most people with disabilities that would be considered for institutionalised living would never go if they had a supportive family that would take care of them. For the persons who do not, their choices are limited to either group living homes, or independent living with the help of a fulltime staff, or institutionalised care in a mental hospital.

One sees that two of the student subjects who were interviewed came from affluent supportive families. After these students graduate they will have the options of living with a staff of full time nurses and aides independently, or of staying within their family. Some students with the independent living option may also try the group home living. This is a less popular option for an extended period of time as it leaves subjects living a less luxurious, dorm room lifestyle. According to the teachers many students try this but will grow out of it after a few years.

The third interviewee comes from a less affluent background that could not afford him the independent living option with a full time staff. Hypethetically, if student C did have the freedom of being able to leave his family he would most likely choose between the group living home or the institutionalised care. Although this student is at a socio-economic disadvantage, there have been a number of programs started in recent years to help assist people with disabilities who are unable to afford living on their own. One example of this is the "Money Follows Persons" program.

This initiative will assist States in their efforts to reduce their reliance on institutional care while developing community-based long-term care opportunities, enabling the elderly and people with disabilities to fully participate in their communities.

The MFP program is an example of a program started by the government to help with the implementation of the Olmstead decision. This program works on a state by state level to help each state fund and implement the program. In order to be accepted to this program one must apply to the regional (region by state) program closest to them in the state. Ohio has 34 regional offices that all give out a significant number of grants. This program has been successfully implemented all over the country and has been used as a useful resource in lessening the inequality of independent living opportunities among the disabled.

Disability Rights Movement Data

In addition to the five student/teacher interviews, I was also able to talk to a disability lawyer from Washington DC and a legal staff person who currently works for the government on creating ways to implement the Olmstead Decision. These interviews were helpful in getting a perspective on the disability movement from a legal point of view. This brings an area of knowledge to my project that I could not have accomplished from talking to the teachers and students at Transition Mission.

Both interviewees seemed optimistic towards the Disability Rights Movement. They were both quick to point out how recently the Olmstead Decision occurred and that large fundamental changes to society in both attitude and physical structure do not occur over night. As we saw with the Civil Rights Movement, not until the Brown vs. Board of Education decision were there substantial changes made working towards the notion of desegregation. Similar to the civil rights movement, these lawyers were hoping that the

Olmstead decision would work similarly to Brown vs the Board of Education, as a launching pad for change. One can already see the early progress to imply that major moves are being made in the Olmstead's Decisions implementation in a government program known as Medicaid.

The Medicaid program UCP was created by the government, and is “serving and advocating for the more than 54 million Americans with disabilities. United Cerebral Palsy (UCP) assists more than 176,000 individuals, as well as their families and communities each day, with services such as job training and placement, physical therapy, individual and family support, early intervention, social and recreation programs, community living, state and local referrals”. Programs such as Medicaid have recently increased their spending towards independent living. “Nationwide, Medicaid served almost 588,000 individuals with intellectual and developmental disabilities in 2007, up 43,000 in just two years. Medicaid spending on people with disabilities rose to \$32.3 billion, from \$28.8 billion in 2005, or about \$55,000 per person for 2007.”⁵ This shows a conscious effort in government spending towards disability as a result of government created programs and pressure created from the Olmstead Decision.

However, the lawyers also acknowledged the weaknesses of the Disability Rights Movement. Similar to the previous research done, Person A highlighted the disability community's lack of organization and its decentralization as a problem. Person A noted the unglorified nature of the position of trying to take charge of organizing the current Disability Rights Movement. The result of such a broad category is that there are many different agendas that the different organizations are trying to get completed. In addition

⁵ <http://www.ucp.org/medicaid/main.cfm>

to this, the position is unpaid. “There is also a surprising amount of animosity and bureaucracy surrounding who is invited to what meetings and who is asked to work on which projects,” said Person A to describe the bureaucracy that often plagues the Disability movement. This again results from the disability community being so large; there are many people who think that they are big shots and want to be heavily involved on a lot of issues. Managing these egos and dealing with this bureaucracy slows the movement down. It makes everything take longer to get done.

Person B enforced the notion that the current changes being implemented were the result of the government and government agencies, rather than change directly created by the disability rights movement. She commended the Disability Rights Movement for the victory of the Olmstead Decision but pointed out that the changes occurring have largely been the result of government organizations, and funding through government run projects. In this Person B used the UCP Medicaid program and the MFP program as examples of successful government programs that were previously talked about.

Analysis of Movement and Results Using Resource Mobilization Theory

Using Snow and Soule’s model of resource mobilization theory for examining the disability rights movement, one sees the movement has a number of both strengths and weaknesses. In using the data and results from the interviews I conducted as well as the tours around the Mount Vernon facilities, I have concluded that the Olmstead Decision does have strong enough support to succeed, and successfully implement independent living for the disabled. Although slightly disorganized, the movement does have the potential to succeed and to continue to progress disability rights based on recent and past

progresss. The movement's strength are their moral, social organizational, and human resources, while the material and cultural resources are the weaknesses when examining the movement.

As mentioned earlier Social Organizational resources are comprised of the public and private institutions and infrastructures that support a social movement. This kind of resource also examines the movement's ability to gain public support and recognition among public officials as well as activists. This is one of the movement's biggest strengths; they have the financial and political backing within politics. As a result of the Olmstead decision a governing body within the government was been created to police and implement independent living. A result of this program is the Money Follows the Person Program and the UCP, which have already made a significant difference in the four years since their creation.

The moral resources of the Disability Rights movement are also an important strength in the movement's future success. Moral resources refers to the legitimacy, support and public endorsement of the movement among the public. This in large part has to do the with public relations of the movement and how good of a job the movement has done in creating a positive image of itself among the public. During the interviews teachers expressed how much different the attitudes have changed surrounding their students and how they are able to engage with the rest of the student body. Students used to fear them, while now they regularly engage with them. This change in public attitude can also be seen in all the publicity the program Transition Mission has gotten in the local papers. The Kenyon program alone has been featured three times in different Knox

County newspapers.⁶ This publicity shows a favorable view of the disabled in the public's eye.

The human resources of the movement is both a strength and a weakness for it. Characterized as “Human resources refers to the three different kinds of human labor that go into making a social movement run. These are generalized labor, specialized labor, and leadership.” The Disability Rights Movement has a lot of specialized labor in the form of lawyers and professional advocates, as seen from two of my interviews. The program also has a lot of activists at the grass roots level, most of whom are disabled themselves. The program lacks a sense of leadership that will take control of the movement and centralize its focus on a specific cause.

The Cultural resource is described as the tactical approach the movement has taken towards achieving success and progressing the movement. This is directly related to the above weakness in leadership. The movement lacks a central governing body or leader that will take charge, the strategy and tactics of the movement suffer. The large scale of the disability community and the lack of money available, that is not provided by the government, is a major weakness.

The material resource of the disability movement is another weakness of the movement. Described by Snow and Soule as consisting of five sub groups; money, supplies, physical space, transportation and employment.” This resource is also intertwined with the lacking cultural and leadership resources. As a result of the movement being separated into different human rights causes; the organizations that deal

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http://www.kenyoncollegian.com/home/index.cfm?event=displayArticlePrinterFriendly&uStory_id=3d44844b-faa5-4e9a-89ac-8cdca4fe99a2

with disability are smaller. They have less money and have a difficult time pulling their resources together. This means the strategy and tactics of the movement is hurt by the lack of money. This results in fewer meetings, strategy sessions, organized events, and less employment.

Snow and Soule also examine the civil rights movement and the significance of the Brown v. board of education decision. In order to fully assess a movement one needs to examine the participation and the dynamics of a social movement. This is an important part of the disability rights movement as there is a large divide between the lawyers who are advocating for the movement and the people who are disabled and directly affected by the law at the grass roots level. The fact is that most of these lawyers are not disabled and have very little contact with the grass roots level. Finding leaders within the movement who are well educated and are capable of legal advocacy while being disabled has been one of the weaknesses of the movement (Foster-Fisherman, Jimenez,Valenti, Kelley 2007: 346).

Many described how it was often difficult to find individuals with disabilities who could take on leadership roles within their communities or organizations. Some leaders were concerned that without an increased emphasis on nurturing leadership within the next generation of people with disabilities, the capacity of the disabilities movement would be weakened.⁷

Looking at the dynamics and the attempt to unify these two sectors of the movement is one of the biggest obstacles standing in the way of the movement's progress and the potential effectiveness of the movement.

Snow and Soule recognized the fact that not every movement is going to be strong in all five resources, but that one needs to assess the context of the movement while

⁷ Foster-Fisherman, Jimenez,Valenti, Kelley, 2007 p.346

applying resource mobilization theory. Here we see the movement is quite strong in Social Organization, Moral, and partially in Human Resources. While the movements weaknesses, are in Human Resources, Material, and Cultural. When examining the weaknesses it is easy to see that they all stem from a common cause. The decentralization of the leadership and the lack of unity among the disability rights organizations. If the Disability Rights Movement can find a way to unify itself it should continue to progress even more than it already has in the ten years since the Olmstead Decision.

Project Reflection

There are a number of areas in my research that can be explored more thoroughly. The Olmstead decision is young; an interesting future study would be tracking the future progress of the decision, and seeing if it continues to be as effective as it has been in the first decade. Other interesting papers on my topic would be on the distribution of funds provided by the state. It would be interesting to see whom the grants for independent living favor, in terms of age demographic and the kinds of disabilities.

Conclusion

In attempting to answer the question, “has the disabilities rights movement been successful in the decade since the Olmstead Decision for the severely disabled?”, one needs to examine the idea of what the definition of success is. For my project I am viewing success as a significant attempt made by the government and the public at changing the physical culture and the social attitude of society towards the disabled. I was looking for evidence in support of the disabled moving towards living independently as part of the greater community within Mount Vernon.

The qualitative research done with three different severely disabled students from different backgrounds as well as two different teachers who live within the Mount Vernon community gave my research an important perspective on the kind of progress the Disability Rights Movement has made at the grass roots level, and in small towns like Mount Vernon. In addition, I also conducted an interview with two people that work closely with disability law. This interview along with the interview of the creator of the Transition Mission program gives my project a well rounded perspective. The interviews were able to help me assess the disability movement from a broader legal perspective and see it in comparison to other similar movements.

The Olmstead decision has been successful and progressed independent living for the disabled significantly in the decade since the Olmstead decision. There is evidence of this in the cultural attitude change, noted by teachers in the high school. There is also evidence of change in the creation of programs such as Transition Mission and MFP, that are working to help make community necessities such as independent living and education an accessible part of normative society for the disabled. Although there is still progress to be made in areas such as public transportation, and eliminating the inequalities that currently favor people of higher socio-economic status, one must keep in mind that change is a process, and not something that occurs overnight, and from a legal and bureaucratic perspective, 10 years is a short period of time.

The disability rights movement has also been successful as a social movement. There are clearly a number of flaws to be improved upon with the movement, surrounding its unity and the centralization of the movement. However, the movement has a lot of positive attributes as we saw from examining it within resource mobilization

theory. The movement should be able to continue its progress and be effective at creating change for its cause in the future.

Bibliography

- An ADA guide for local governments : [making community emergency preparedness and response programs accessible to people with disabilities.]*. Washington DC: Civil Rights Division, Department of Justice, 2007. Print
- Cook, Emily. "The Dual Stage of Social Movements." (2003): 1-14. Print
- Davis, Gerald F., Doug McAdam, W. R. Scott, and Mayer N. Zald. *Social Movements and Organisation Theory*. New York: Cambridge UP, 2005. Print.
- Hayashi, Reiko. "MiCASSA- My Home." *Journal of Social Work in Disability Work Education* 6.1/2 (2007): 35-52. Print.
- Johnston, Hank, and John A. Noakes. *Frames of Protest: social movements and the framing perspective*. Oxford: Rowman and Littlefield INC., 2005. Print.
- Olmstead v. L.C.* Judge David L. Bazelon Center for Mental Health Law. Web.
<<http://www.bazelon.org/issues/disabilityrights/incourt/olmstead/index.htm>>.
- Medical Rights Contribution. *Care Management Journals* 6.1 (2005): 29-35. Print.
- Munday, Jennie. "Identity In Focus: The Use of Focus Groups to Study the Construction of Collective Identity." *Sociology* 40.1 (2006): 89-105. Print.
- Palley, Elizabeth, and Phillip A. Rozario. "The Application of the Olmstead Decision on Housing and Eldercare." *The Journal of Gerontological Social Work* 49.1/2: 81-96. Print.
- People with disabilities -- Legal status, laws, etc. -- United States*. Washington DC:
- Snow, David A., and Sarah A. Soule. *A Primer on Social Movements*. New York: W.W. Norton and Company, 2010. Print.

"Study on Human Rights and Disability." *Office of the United Nations High Commissioner for Human Rights*. OHCHR. Web.

<<http://www2.ohchr.org/english/issues/disability/study.htm>>.

Teitlebaum, Joel, Taylor Burke, and Sara Rosenbaum. "'Olmstead v L.C. And the Americans with Disabilities Act: Implications for Public Health Policy and Practice,'" *Public Health Reports* 119.3 (2004): 371-74. Print.

University of California Berkeley. "[Http://bancroft.berkeley.edu/collections/drilm/](http://bancroft.berkeley.edu/collections/drilm/)." *The disabilities rights and independent living movement*. University of California Berkeley. Web. <<http://http://bancroft.berkeley.edu/collections/drilm/>>.