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Nancy A. Cheeseman

Disability, Equity, and Education

Submitted in partial fulfillment
of the requirements of
Doctor of Education

National College of Education
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# Abstract

What is the historical connection between deinstitutionalization and the Olmstead decision? The purpose of this study was to examine and analyze policy within a historical perspective the connections between institutional care, deinstitutionalization, the Olmstead decision, and the effect on persons with intellectual disabilities lived experience, in the state of Illinois.

The data collected include, the transcripts of interviews with four participants, artifacts from policy documents and historical papers accessed from the Disability Museum online journals. The creation of a table for use in coding themes as associated with 5 (out of 18) core concepts for disability policy.

The Olmstead decision and the Ligas Decree provide a framework to identify barriers and gaps in state policy. The findings indicate establishing a formal Olmstead Plan, which could prevent further litigations. Limitations to this study consist of small sample size. Recommendations include, to reconvene a committee of stakeholders and self-advocates, to investigate using the Blueprint as a guide in development of an established Olmstead Plan, in effort to prevent future litigations and provide sustainability, in Illinois.

# Acknowledgements

My dissertation journey is a culmination of my personal and professional life. There are many who traveled this road with me on my good days and some very trying experiences. My niece, Jessica told me, “ the P in PhD stands for Persistence”.  She is correct. Persistence and determination to finish something started a long time ago.

This paper is dedicated to Christine, your insight, humor, and encouragement provided me with the confidence to move forward in the field of advocacy and disability. Our travels to Springfield to make our voices heard for early intervention services for infants and young children with disabilities and their families made me stronger, wiser, and the best advocate, my son, Casey could have. Christine passed away, however she will always be in my thoughts, actions, and heart.

Dr. Valerie Owen, who told me when I started the program, that perservence and persistence will pay off to get into the club. Do not let anyone tell you that you cannot finish. She has been the force to keep me on track, during the many tests of human emotions connected to my life experiences. I appreciate her humor and kick in the pants attititude. Valerie, I am there, at the end. Thank you for always being there. You took me from there to here.

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For my family, where would I be without your patience, understanding and being my cheerleading team, during my meltdowns and high anxiety to finish what I dreamed impossible. Sally, thank you for always providing me affirmations and never giving up on my abilitiy to finish my dissertation. Your constant message, “Believe in yourself, mom, you can do this”. Polly, your humor and easy going personality keeps me afloat when I needed it the most. Jacki, Ric and Kennedy, now I will have time to be a grandparent.

John, my husband, my best friend, and editor for this journey, I finished! Our life can now return to something that resembles a sense of quiet and accomplishment. Thank you for your patience these past few years, your encouragement to finish and move on to our next adventure. In addition, most of all for the years we have spent learning how to be parents to a child with a disability. We somehow managed to bring up an amazing young man, who is confident, independent, provides unconditional love and respect, and forgives easily.

To my mother and dad, I wish you could be here to see my grand finale. I know you have been looking down and nudging me along. I miss you both.

And finally, Casey, who continues to show determination in a variety of ways. I hope someday others will get to know your humor, patience, persistence, forgiveness, insight and acceptance of yourself and others. Someday others will get to know all your abilities and not (dis)ability. You have forever changed my life for the better. You are a leader.

# Dedication

For Christine, Casey,  DC, and Danny

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# Chapter One

"*We live in a world that recedes into the past and extends into the future, rather than pitting ourselves against history, and therefore, we need to remember, recollect, and recall it. This is not an epistemological quest, but an ontological one, as we are historical. This address of tradition is not just something arching from before, for we are in tradition" (Moules, 2002, p. 2)*

History provides us with a reference in which to build constructs of our worldview, based on the dominant cultures' values, beliefs, and a social system relevant to a specific agenda. Language and communication structures drive the larger social system, which can dictate inclusionary or exclusionary practices for those with disabilities (Stiker, 1999). Rather than push aside or forget the historical implications society placed on those with disabilities, we need to embrace the knowledge left behind. We are in some way a part of the past,  in order to change the present, which can  reform the future. History reveals exclusionary social practices based on normative values, about who fits in and who does not in economics and medical practices. There is the perception that if a person with a disability wants to leave an institution to live in the community can be denied their request, because of state policy decisions and the lack of money to support the necessary services to live independently. The underlying message to the person is that the choice of where to live, work and socialize, is like saying, "he or she may not be worth the expense" (Shoultz, Walker, Taylor & Larson, 2005).

Bagenstos (2009) articulates, that historically people with disabilities were excluded, pushed aside, and ignored because of imaginary fear, benevolent charity and were destined to live in out of the way facilities many miles from family or community. Historically, for people with intellectual disabilities, the provision of services rested on the decisions and management of family members, professionals, and policy-makers, which generally resulted in the person residing in a state facility or institution. Bredberg (1999) notes, "Contemporary writers of disability often are critical of institutional care of those with disabilities, however continue to represent disability history as predominately the history of institutional practices" (p.191). Prior to institutions, many people with intellectual disabilities were living at home with their families, not in large institutions. My preliminary examination of social policy and practice indicates involvement of the family. Although some disability scholars strive for inquiry from a lived experience void the family unit, this study does involve in part from my experiences with my son.

### Neighborhood memories.

Growing up in a new low-middle class neighborhood, I always felt as though I did not belong, but wondered how I fit in. I felt different in school and the "rich kids" told me often, because my dad worked for a lumber corporation, as a laborer. The "rich kids" would remind me of my status by making fun of my clothes and appearance. I remember my mother always telling me "Rise above this as there maybe something wrong in their life that makes them want to single you out". I guess by today's standard this is bullying. These taunts made me stronger, however lonely, as I tried to figure out what was wrong with me. I did not delight in the excitement the rest of the kids did in tormenting someone less fortunate. I kept trying to understand why some kids did not have compassion or empathy for others, including children in my elementary school with physical, intellectual, emotional and health related disabilities. These outcasts, the ones chosen for the pleasure of teasing, were laughed at, and ridiculed even by the teachers. I had no fear of "these" kids, but I could not go to their house to play. I wonder if they felt similar to me, tormented and lonely. I was unable to understand but never had the opportunity to ask because eventually they disappeared from my school. As I look back, I realize this could be a reason why

I was always seeking to help the underdog, someone who needed help physically, or verbally, someone who needed an advocate or friend.

People would whisper about how the “others” went to a special school away from their families. In a way, I was a bit envious with the thought of going away to a special school, even though I had no clue what a special school was. I just wanted to get out of my school, leave, run away from the everyday stress. There was one kid with cerebral palsy who stayed behind. He walked with a heavy awkward brace on his left leg and a horrible scar from the top of his head to behind his ear. His gait was slow and methodical, with a heavy limp, all of which accented the huge brace on his leg. His left arm and hand curved like the letter s only sideways, he held them closely to his chest or when excited would attempt to wave in the air. The kids called him Spaz. I called him Danny.

In the beginning, he thought the kids were playing; however, over the years he came to understand they were not. All the harmful taunts and names, which he had thought of as play, now made him bitter and angry. No more laughter, no more chatter, just a hurried clumsy walk with his briefcase full of textbooks and paper. He graduated from high school with me and got a job as a greeter at a bank. However, he never acknowledged my greetings when I saw him. As young adults, our lives were changing and I moved away. To this day, I do not know what became of him. No one in the neighborhood ever discussed him again.

### Overview of Dunning State Hospital.

Some of the “others” kids went to a place known as “Dunning”. I did not know what Dunning was other than that it was a fearful looking place. A high iron fence with open slats, through which the people behind would reach out to touch you, or grab you, many walking around talking to themselves, running in circles, talking nonsense, or asking for money or help to get out. As I grew up, I came to understand what this place was. It was an institution. This institution was where the “crazy people” or “retarded” lived, or were incarcerated, as if in a prison.

On the Northwest side of Chicago, Andrew Dunning donated forty acres of land, on which he intended to build a house/facility for those who had a difficult time adjusting to society: unwed mothers, those sick with tuberculosis, orphans, old people, and veterans. In 1912, the City of Chicago acquired the facility and land and named it Chicago State Hospital Dunning. The numbers of residents increased to 1,000 patients. The patients came to Dunning via the Chicago, Milwaukee and St. Paul railways, known during this era as the “crazy train” (Kelly, 2003).

By all accounts, Dunning became a place of horror, fear and relentless corruption. The neighborhood grew slowly because of the poor reputation and stigma surrounding Dunning with its eight-foot high iron fence to keep the insane, the poor, the intellectually disabled in and the “normal” out. Many in the neighborhood became so consumed with fear, that some kept weapons near their beds and locked all their doors. When the siren would loudly announce to the neighborhood that someone had escaped, everyone who was outside quickly ran for cover. I recall my parents singing to us “Dunning, Dunning open your gates, here comes (some unsuspecting person’s name) on roller skates”. If a child misbehaved the punishment was the verbal threat of going to Dunning “where all the crazy people are kept”. This tune continues to bring back memories as the method to control and discipline children’s behavior during the late 1950’s and early 1960’s.

### Importance of Study.

My first child, my son, was born healthy, all extremities intact, smiles, and bright eyes: handsome. Four days later, his world and mine turned upside-down. The doctor admitted him to the hospital for low blood sugar, which gave rise to a massive status epileptic seizure, resulting in significant injury to the frontal and right lobes of his brain. Upon hearing the diagnosis all that ran through my mind was Dunning, retardation and the kid I went to school with. My feelings and thoughts were irrational, negative thoughts including those kick-in-the stomach nauseous feelings one may experience when something horrible has happened. The doctor sat there, not too eager to discuss prognosis, so I opened the door asking, "Will he be retarded?"

The answer from this medical professional was not a firm yes or no, only that they would monitor my son's progress. Then, I experienced the moment of "No" not me followed by: the thought of the institution with all those strange and peculiar people. Would my son end up there? I had heard of doctors telling families to institutionalize their "damaged" babies: it would be better for all members of the family as there would be no "burden". Some of my own family members would look at my son and whisper behind my back, "He will never amount to anything, they should put him away." Even a mother's group that the doctor sent me to was just another reminder: "We were different" we had become part of a new group, a new way of life, that of disability. I was not going to institutionalize.

Our lives were now changed. There was a shift in how my son and family were viewed. We became viewed as a deficit model. This deficit model views my son and my family as sick, needing a cure or fixing, and beholden to specialists with the skills to cure. My background was not in medicine, education, health or rehabilitation. I was an accountant and my husband was a union employee. What did we know about the care of a baby with a disability? Nothing. We were at the medical community's mercy for information, diagnosis, prognosis, cures and remedies. Wickham-Searl (1992) describes this relationship as, "Most professionals assume that families are engaged in never-ending struggles to relieve devastating personal and social problems that accompany the presence of a person with special needs in a family" (p.251). Doctors subjected us to criticism for not having done enough to prevent this, but how could we prevent something we did not know about? The medical community viewed us as weak and in constant need of help or grieving for the ideal child. Our family was not weak. Yes, we grieved but proactively by making the medical community uncomfortable when we questioned their practices.

Since these events were 30 years ago, I needed to discover a new way of thinking. William James ( 1842/1910 ) quotes, "that the greatest discovery of any generation is that a human can alter his life by altering his attitudes". This revelation prompted me to change careers, become knowledgeable in a new language of disability and ways of life. I began with the goal of educating other families about the benefits of keeping their children at home with them, especially in light of very poor conditions in massive, overcrowded institutions where neglect, abuse and death were common. I consider this my initiation into the Disability Rights Movement and advocacy. The use and power of personal narrative is what drives me to reach out, speak up and educate those who need to hear from someone who has lived with someone who has a disability.

Hendry (2010) writes:

> Narrative research is the first and oldest form of inquiry. Narrative means "to account" and is derived from the term *gno*, meaning to know. The oral storytelling traditions of early man were narrative inquiries that sought to address questions of meaning and knowing. From the beginning, narrative embodied multiple ways of knowing (p.103).

Storytelling or personal narratives provide us in making meaning out of situations, bad or good. It is a way to understand our worldviews, beliefs or values, especially if life has changed in ways we cannot comprehend. It is my intent to analyze policy and personal narratives from those whose lived experiences focused on advocating for system change in how choice, dreams and independence are for all, not a select few.

I was guardian of my son until in 2010, when my son requested his independence or emancipation to live by making his own choices and decisions.. This announcement brought many mixed emotions tied to a wonderful, huge step for a young man with challenging disabilities. Today, he has an apartment, a group of friends and social life, a job he enjoys and that provides him with the sense of worth. This is what I always envisioned for him: no institutions, no group home, and no nursing facility. However, as a parent, you are left with many lingering questions. How will he remain safe and secure in his own world? How will he continue to develop the cognitive and social skills necessary to remain alert to those who prey on the vulnerable? Will he continue to be independent and self-reliant in order to stay in his home and community? There are other families, in Illinois, who have been on similar journeys, with disability and face the same questions.

## Purpose of Study.

The Supreme Court ruling of L.C. v Olmstead, in 1999, stipulated the states develop plans to provide the opportunity for persons with disabilities to choose where to live, including supports for services within their community. The purpose of this study is to examine and analyze policy within a historical perspective into the connections between institutional care, deinstitutionalization and the State of Illinois' lack of an established Olmstead plan or policy. The State of Illinois continues to face litigation for non-compliance with ADA and Olmstead regarding alternative choices for persons with intellectual disabilities. For my son, we knew the prospects and limitations for employment, friendship, and community living in the state of Illinois, because of the inconsistent policies and plans for people with disabilities. The lack of a working plan led people to file state lawsuits. And yet, even today, the state of Illinois fails to accommodate citizens with disabilities in a community setting.

In 2005, a lawsuit filed by nine persons with intellectual and developmental disabilities known as, Ligas v Maram, claimed these nine people, who lived in a large private, state-funded facility were not provided with choices or community options. The lawsuit settled in 2010, resulted in an order for the state to guarantee that 3,000 additional citizens would receive support for independent living. The state of Illinois most recently closed the Howe Developmental Center in Tinley Park, Illinois. These closings met much protest from families, who did not want their son or daughter moved to a home in the community. The Voices of the Retarded is an organization made up of family members, professionals and unions. This group is very outspoken to the details of Olmstead and will be researched to provide me with another side to impact on policy issues for Illinois.

Chapter Two will be the methodology section, including the restated purpose of study and research questions; the data collection consisting of conducting interviews with one of the plantiff’s in the Ligas v. Maram; a representative from a state advocacy; review of the organization Voices of the Retarded (VOR) website; an interview with the CEO of a major provider of direct service organization and the program director for adminstation of the Ligas Implementation Plan; the examination of the Illinois Council on Developmental Disabilities Blueprint; the Consent Decree and court monitor quarterly reports for compliance.

Chapter Three provides a brief overview of the history of institutional care in America and the advent of the stigmatization of individuals with the label of intellectual and developmental disability. Many professionals in the social science, education and rehabilitation fields have written extensively on the history of institutionalization. Large institutions emerged from this particular historical context; and to deny the existence of this history is to undervalue the existence, stigma, and oppression of people with intellectual and developmental disabilities and their lived experience, within the walls of massive institutions. It is necessary to understand the various social and economic policies in history regarding people with the label of “feeble-minded”, “idiots”, and “mentally retarded” and how the labels and diagnosis were socially constructed.

Chapter Four will provide a brief historical review of the institutional and de-institutionalization reform in the State of Illinois and the facilities (i.e. the Chicago State Hospital, aka Dunning, the Lincoln Developmental Center, previously known as the Illinois Asylum for the Feeble-minded and the Howe Developmental Center). During the institutional phase, circa 1950-1970, and there was an increase in advocacy organization formed by families, who initiated the reforms leading to the deinstitutionalization movement with the legal cases of Wyatt v Stickney (1972), and Pennsylvania Association for Retarded Children (PARC) v The Commonwealth of Pennsylvania (1971). PARC is a state organization under the national group organized in 1950 to address concerns of health, education, and well being of children with disabilities. Illinois has a chapter known as ARC of Illinois which is a proactive group in addressing the needs of all persons with disabilities including being instrumental in the legal suit of Ligas v Maram.

In order to understand the politics associated with Olmstead, the closing of large residential facilities and the battles between parents, politicians, and social agencies in Illinois there needs to be an analysis of existing policy. This chapter will address the background and an increase in legal suits filed against Illinois; the position self-advocates and their families take related to developing policy to meet the requirements of Olmstead and choice of community options.

The chapter will end with the discussion of the lawsuit filed by Lois Curtis and Elaine Wilson, women who were diagnosed with “mental retardation” and mental illness. Lois and Elaine filed suit against the State of Georgia for failure to provide services in accordance with Title II of the American with Disabilities Act, in their community of choice. The lawsuit known as Olmstead v L.C. and E. W led to the signing of the Olmstead Law, 1999.

Chapter Five will discuss the findings of the research and make connections to overarching research questions.

In chapter six, I will provide a discussion and summary for future implications to the self-advocacy movements, policy agendas, and predictions for further research.

# Chapter Two

## Methodology

### Research questions.

As stated in Chapter 1, the history of institutionalization had a significant impact on many persons with disabilities, their families, as well as the development of federal and state agencies and a vast number of other organizations. The topic of deinstitutionalization reform, the Olmstead law and the lack of an effective plan and policy, in Illinois, influenced the following questions for analysis:

1. What are the historical underpinnings of inequity and marginalization of people with intellectual disabilities? What is the role of social and economic factors?
2. What is the historical connection between deinstitutionalization and the Olmstead decision? How does the historical connection between oppression, institutionalization and the Olmstead decision currently affect the lived experience of persons with intellectual disabilities?
3. In what ways did persons with intellectual disabilities, advocates (pro and con), families/parents and other key stakeholders impact steps to make changes to institutional and community care, in the state of Illinois?
4. How might an Olmstead policy impact future legal judgments, in the state of Illinois?

The purpose of this study was to conduct the necessary research within the historical venue and policy analysis in order to complete the requirements of the doctoral program. The outcome of this research has provided information to address questions and continue to identify barriers and gaps in the policy or lack of a consistent policy related to the requirements of the Olmstead Law for persons with disabilities in the State of Illinois

**Historical Research.**

McDowell (2002) defined historical research as "a systematic inquiry into the past and an attempt to separate true from fictionalized accounts of historical events, based upon the examination of a wide range of relevant source material" (p.5). History is based on past beliefs, culture and ideas, which provide us with an understanding of the past and how we can learn from these past mistakes, in order to anticipate and appreciate the present. Marshall and Rossman (2006) state the following:

> Historical analysis is particularly useful in obtaining knowledge of unexamined areas and in reexamining questions for which answers are not as definite as desired. It allows for systematic and direct classification of data. Historical research traditions demand procedures to verify the accuracy of statements of the past, to establish relationships, and to determine the direction of cause-and-effect relationships. Many research studies have a historical base or context, so systematic historical analysis enhances the trustworthiness and credibility of a study (p.119).

I cannot predict the future, but I can use the artifacts of historical research to examine what is important and interpret emerging patterns in social, political and economic change to foster an appreciation for future change (McDowell 2002; Taylor & Bogdan, 1998; Marshall & Rossman, 2006).

"History is more of an art than science, that has a closer affinity with literary traditions, and that the art of writing and the use of imagination are more important in historical research than the method of investigation. Social scientists share a belief in the need to explain the significance of events, and not merely describe them" (McDowell, 2002, 17). "Historical analysis cannot use direct observation, and there is no way to test a historical hypothesis" (Marshall & Rossman, 2006, p.119). I am not a trained historian, but a novice, in the area of historical research. I want to develop a worthy display of interpretive qualitative data, including a review of newspaper articles; policy and legal documents; and interviews with people directly associated with the Ligas lawsuit. This will be a challenging feat, as will trusting my basic skills to decide which documents, policy reports, legal documents etc. are to be studied for content, and useful and reliable information.

Howell & Prevenier (2001) state,” all cultures, all people, tell stories about themselves, and it is these stories that help provide the meanings that make a culture” (p.1). In association with other qualitative methods of research, this paradigm allows me to recount and interpret a lived experience, to discover and create the past, and experience how these events have a relationship to the present. The data collected will include the voices of those who share experiences of living within the confines of institutional care, who experienced the denial of their ability to make choices, and who ultimately self-advocated seeking legal action in order to improve their lives and the lives of others with intellectual disabilities. The voices of DC.(one of the nine plaintiffs in the Ligas case), key stakeholders in the advocacy movement, and service providers, were interviewed by either in-person or via telephone with a set of pre-determined interview questions. The interviews will be semi-structured to enable the follow up questions.

Guba and Lincoln in *Competing Paradigms in Qualitative Research* discuss the heavy emphasis on quantitative measures in science, and the need to reserve a description for a type of method between quantitative and qualitative, known as a secondary to research paradigm. They define this paradigm as “the basic belief system or worldview that guides the investigator, not only the choice of method, but in ontologically and epistemologically fundamental ways” (p.105).

Moules indicates that an investigator has developed a belief system and a worldview in which his or her inquiry will take shape. The foundational basis for this reality is the relationship between the historical events and the shaping of the social, economic and political inquiry. A social justice model provides the foundation for my own inquiry. The institutional care practices, within Illinois and nationally, maintain a focus on the economic and political ramifications of shutting down large facilities, such as jobs within the community. It is my intent to review various economic and political documents related to the lack of sufficient plans for community choice and living opportunities.

### Policy Research.

Patton (1993) describes the concept of policy analysis as a process by which “we identify and evaluate alternative policies or programs that are intended to lessen or resolve social, economic, or physical problems”. He continues by defining the term “Policy analysis is commonly referred to the outcome of the analytical process” (p.21). Gabel (2008) refers to policy activism as “Coming to full awareness of and engagement with the ways in which policy shapes and reflects to us the world in which we live and the ways in which members of social movements can act to change the world through policy work and toward the goal of a just society” (pp.311,312). The reality of this non-traditional historical policy analysis research will provide a beginning inquiry to understand the lack of policy structure associated with the Olmstead Law, community based living and the implications for people with disabilities, in Illinois.

### Participants.

To enhance and provide context of the lived experience to this research, an in person interview was conducted with one of the ligtigants for Ligas, phone interviews were conducted with the CEO of a state advocacy agency, the CEO of a major service provider and the program director of the organization awarded to provide compliance for the Ligas Implementation plan for the class members.

### Data Collection.

The collection of historical data sources will consist of: (a) documents, newspaper and historical articles; (b) policy and legal documents related to various past legislation such as: Americans with Disabilities Act (ADA), Ligas v Maram, Ligas Consent Decree, and Implementation Plan, Court Monitor Quarterly Reports, and Olmstead law; (c) current Blueprint for Illinois; (d) letters to the editor, opinion related documents, speeches, public opinion polls. Marshall and Rossman (2006) discuss how narrative inquiry may rely on journal records, photographs, letters and life histories.

A semi-structured questionnaire was developed to provide this researcher with areas to focus on during the interview process. One set of questions was developed for the litigant and one set for the providers. The set of questions for the litigant were developed and presented to the litigant for his understanding. The litigants parents were both present during the interview. This researcher used a semi-structured face to face interview format with the litigant. The semi-structure interview questionnaire was conducted with the providers, however via telephone, due to the researcher living out of state and the providers time schedule. The interview questions were sent via email to all participants in advance which provides them with an opportunity to review for content and context.

Examples of questions for the litigant to begin the interviews included, but were not limited to: Tell me about your experience of living in a group home or other place? To what extent did this experience contribute to your understanding of having a choice of where you could live? As a result of this understanding how did you become involved in filing the lawsuit against the state of Illinois? What does the state of Illinois need to do to improve services and establish an Olmstead plan for persons with disabilities? The question set sent to the litigant was not modified, because I did not know DC's reading level and I wanted him to feel included in the process, like everyone else. I did not want to "dumb down" the questions, so I modified my questions, when we met.

Examples of questions for key stakeholders and the service provider included however were not limited to: Tell me what role (responsibility) you have/had in the the state of Illinois? To what extent does this role (responsibility) play in development of an Olmstead plan? How do self-advocates contribute to the litigations filed against the state for the lack of a working plan? As a result of litgation against the state and any current settlements, how can these be applied to develop an efficient and much needed plan? What is needed from various stakeholders to implement a plan? The state continues to revise the Blueprint for change, how does this impact future policy endeavors? What do you see for the future of Olmstead in the state?

All interviews were recorded and transcribed by an outside firm known as Rev, an online transcription service. The transcriptions were reviewed and coded according to the Core Concepts chosen from Stowe et.al (2001) model for analyzing policy concerning persons with disabilities and their families.

### Terminology.

This study includes terms such as "idiots, morons, feebleminded, deviant and mental retardation". These words reflect the ideology and common usage in a given historical period. In no way are they intended to offend the reader. To change the terminology is to alter fundamentally the context of their use, at a specific point in time. Bogdan and Taylor (1976) define "a mentally retarded person as one who has been labeled as such according to rather than arbitrarily created and applied criteria" (p.157) in other words a term which is socially constructed.

# Chapter Three

## The rise of the institutional care system.

### Introduction to the institutional system of care.

In this chapter, I intend to provide the necessary historical journey to demonstrate the inequities and marginalization people with intellectual disabilities endured due to social and economic factors. Historical documents provide insight into reasons for placing persons with intellectual disabilities in institutions, such as social control and the belief this population could not add to the economy of the nation. I conducted research on the Disability Museum website and searched for documents using key words of aslyums, idiots, institutions, retardartion in order to access historical material. I used the terminology of the time because for the dates in time newer language is not recognized. The museum website provides a wealth of historical writings by original authors such as those referenced in my study. The information was a gateway to understanding how institutional care began in America.

Persons with intellectual and developemental disabilities are seen as a deficit and drain on the social and economic policies. Taylor (2001) states, “the question of segregation versus integration, or institutions versus the community, was resolved many years ago, in my opinion” (p.15). Many professionals in the social sciences, education and rehabilitation have written about life in an institution and the impact on those who were patients. I do not wish to belabor the topic of institutionalization, the dehumanizing effect on many, however, not to provide some historical information is to do injustice to people with disabilities who may still reside in an institutional care setting. The purpose of this chapter will demonstrate that disability is a social construct (Taylor, 2004, Connor, Gabel, Gallagher and Morton, 2009). Connor, Gable, Gallagher, & Morton (2009) discuss this perspective “as articulated in the social model of disability, diametrically opposes the medical model by virtue of its re-conceptualization of disability as inevitably values-laden and historically/culturally situated. Thus, disability is not a "thing" or condition people have, but instead a social negation serving the powerful ideological commitments and political aims" (p.447).

This historical information will provide a gateway to events leading to the passage of the American with Disabilities Act, including significant background of the Olmstead Act. The comment by Taylor reflects the underlying premise of my research into the lack of a policy structure associated with Olmstead Law and the Ligas case, and implications for people with disabilities in the State of Illinois.

### The early years.

The building of institutions began as a benevolent, moral, and charitable way for those of wealth and majority class to ensure their path to heaven if they provided for the less fortunate. Édouard Séguin (1812-1880) had a concept to train the feeble-minded for community life, however over the years this model and social policy changed to include classification and labels developed in intelligence testing.

Henry Goddard's (1866-1957) introduction of intelligence tests was very much a part of our country's fabric, in fact a very profitable commodity. Franco (1985) reports shortcomings to intellectual testing and academic ability, especially in the use of the instruments demonstrating that the distinction between testing and ability is not synonymous with intelligence. According to Brooks (2007), there has been no definitive evidence proving that IQ is linked to heredity, adaptability, or abstract thinking skills.

Kanner (1964) reports that Goddard's 1912 study of the Kallikak family, also, sparked a "eugenic alarm" in his characterizations as, the picture of feeble-mindedness, a menace to society and “a cesspool from which rose unending swarm of criminals, drunkards, paupers, and breeders of ever more defectives” (p.141). The stigma and label associated with by the initiation of testing, immigration, and an inability to cope in the community continued to grow until another paradigm shift. The institutions or schools became custodial in nature and corruption, abuse, and neglect, even death, became the norm.

### Historical roots for institutional care model.

The institutional care model for persons with intellectual disabilities, in the United States, began in 1846, with the arrival of Édouard Séguin. Séguin came to the United States at the request of George Sumner and Samuel Gridley Howe, who were impressed with the work done by Séguin at the Bicetre Asylum, in France. Seguin (1856) believed the “moral training of will” of the feeble-minded or idiots, could increase, through the development of methods and interactions with their physiological or muscular systems. Moral treatment meant addressing aspects of the physical and mental health of an individual in a holistic and humane approach. This was a method to develop the potential of individuals with disabilities, while not just focusing on the level of intellect (Sacks, 2009).

Séguin (1856) elaborated on the meaning of moral treatment in *Origins of the treatment and Training of Idiots* with discussion and interpretation of the mysteries of the laws of philosophical medicine. He describes these laws as:

> Unity of God, manifested in his three principal attributes; unity of man in his three manifestations of being; the idiot, like other men, a likeness of God, infirm in the modes of expression of his trinity. 1st. Infirm in his mobility and sensibility. 2d. Infirm in his perception and his reasoning. 3d. Infirm in his afflictions and will.

During this century the philosophical beliefs of benevolence, charity, and morality were practiced by those wishing to become part of God’s work.

He states, “moral volition, superseded by a negative will; that in which, the treatment of an idiot essentially consists is, in changing his negative will into an affirmative one, his will of loneliness into a will of sociability, and usefulness; such is the object of moral training” (pp. 6, 35), all in the name of Christian charity.

Linus P. Brockett (1855) article, *Idiots and Institutions for their Training*, discuss factors related to the work of Itard and Seguin which follows the concepts of attention to the humane and noble philanthropic movement to educate those who suffer from idiocy. He continues to discuss how the development of unsanitary conditions, lack of proper nutrition, and extreme poverty leads to idiocy. The arrival of Seguin to America in 1848 to establish the Pennsylvania School for Idiots was thought to be a successful route to “training this unfortunate class” (p.5). Dr. Samuel Gridley Howe followed Seguin’s method of training and instruction by maintaining oversight at the school in Massachusetts. Séguin, Howe, and Wilbur had the idea to provide for this class of persons through philanthropic and humane measures.

This philosophical thinking led to the New York legislature to begin developing institutions. Along with construction of these structures came definitions for idiocy, based on Séguin’s work, as described in Brockett’s 1855 article, “the idiot is an individual who knows nothing, can do nothing, and wishes nothing; and every idiot approaches more or less to this maximum of incapacity” (pp 3, 24). This definition met with objections so another one was considered briefly, “[Idiocy is the] result of an infirmity of the body which prevents, to a greater or less extent, the development of the physical, moral, and intellectual powers” (pp.3, 24). This definition provided those who supported a humane approach to locate numbers of persons defined as idiots in Europe and America. The numbers were staggering in Boston according to reports “out of 170,000 people only 21 people were identified, however a town of 5,000 reports

25 cases" (pp. 3, 25). The areas of poverty, inter-marriage, hereditary tendency, attempts to destroy the unborn, ignorance, and the result of those who sought wealth and neglected their offspring were identified as  the causes for idiocy or "in short our world is the direct result of violation of the physical and moral laws which govern our being" (pp. 4, 29).

In 1854 Harpers *New Monthly Magazine*, discussed religious reasons to care for those with idiocy as  "which for any of us we may do something toward raising the lowest, and blessing the most afflicted, members of our race" (pp. 6, 11). The article continues to provide undertstanding of the maternal feelings associated, with knowing the child may be disabled,  as experiencing a great sadness however, rejection and pity are necessary for survival. The fate of this child rests with the mother and her choice of keeping the child or surrendering to others for protection and care.

The building of these institutions soon moved away and changed from the concept of schools to train residents for community living because the residents were demonstrating the inability to adjust to the ways of living in the community. The developmental concept set for residents deteriorated into a model of pity and charity. The disabled came to be viewed as people incapable of living among community members; they were considered "innocent victims of parental sin and fate". This reinforced the notion of no schooling but more protection and loving care ( Wolfensberger, 1969 ). The term "school" became asylum, a place for protection from all humanity, a place where no human rights exist, including marrying and reproducing offspring. This place becomes one of custodial care. Wolfensberger states, "The protective model emphasized benevolent shelter, however, it bore the seeds of three dangerous trends: 1. Isolation, 2. Enlargement, and 3. Economization" (p.29).

### The intent of building institutions.

During 1870 and Séguin’s tenure of establishing moral treatment and training: two institutions were built in Massachusetts, one in Connecticut, two in New York, one in Pennsylvania, one in Ohio, one in Illinois and one in Kentucky, each housing and providing instruction to over one thousand children. The one in New York was built for public charity and one in Barre, Massachusetts was private and self-supporting.

The delivery of a humane and holistic model began with the construction of structures, that resembled grand resort looking buildings that included plenty of light, airy rooms, plenty of land for completing work, such as farming, dairy, and gardening. Byrom (2001) refers to the creation of institutions in 1890 as “hospital-schools” with the mission to provide vocational training, education, and work. Individuals who lived on the property used to perform work, which provided them with a sense of purpose. These large structures known as asylums housed people with either mental illness or mental retardation (Wolfensberger, 1969; Sacks, 2009 ).

The construction of these Victorian structures provided stability that many residents had not known before. Many residents came to the asylums either by choice or by commitment. Families unable to care for an individual with disabilities had no alternative other than to relinquish custody to these large institutions, in hope that this individual would be cared for in a humane environment. Soon these structures, which represented a safe refuge, began to resemble small towns, which could house as many as 14,000 patients at one time (Sacks, 2009).

As the 20th century progressed, there was a shift in the original philosophical vision of an asylum, intended for safety, retreat, sanctuary, and refuge, to a model of a state hospital or institution. This final construction of state hospitals or institutions and the societal implications of this era, created a shift to a new philosophical vision of institutional care, due to the large numbers of patients, lack of staff, medical personnel, funding, and inadequate, corrupt management of everyday events (Sacks, 2009). During this time, the building of massive structures became the norm across the country, in efforts to provide services to a large marginalized population. Many who would enter what they thought to be a safe environment, and with the intent of leaving someday, most likely experienced a life of institutionalization, until death.

In her 1843 Memorial to the Legislature of Massachusetts, Dorothea Dix (as cited in Voices from the past, 2006) proceeded to describe her journey to almshouses, prisons and asylums, which housed persons with intellectual disabilities. She states, " I tell what I have seen—painful and as shocking as the details often are—that from them you feel more deeply the imperative obligation which lies upon you to prevent the possibility of a repetition or continuance of such outrages upon humanity". Dix continues by providing examples of extreme filth, persons in closets, cages, cellars, those who are chained, naked, beaten, and lashed into obedience. She suggests prisons and other places housing persons not fit for these environments are a product of a "defective legislation which perpetuates and multiplies these abuses". Dix has documented the environments of Springfield, Northampton, Williamsburg, Rutland, Sterling, Burlington, Concord, Lincoln, Medford, Pepperell, Brookfield, and Granville as institutions of severe neglect and other inhumane treatment of residents.

This message to the Legislature was a demonstration of the model of care, which was not in the vision of Seguin, Itard, and Pinel, who supported the concepts known as "moral treatment". This message provided Dix with the opportunity to express her opinions on the state of society within the realm of "moral authority and special responsibility to the most vulnerable citizens of the country". Dix could not address the legislature formally, because at the time women had no rights to participate in any form of political engagement; male representatives gave all formal speeches. Dix's involvement brought forward, the "appalling conditions in existing institutions and promoted the inherent value of compassionate care".

### Understanding the history of institutional care model.

Philanthropists and doctors of the late nineteenth to early twentieth centuries discussed and argued over the topic of care and development of those labeled "feeble-minded" or "idiots". The societal attitudes of benevolence, charity and innate good of all people, shifted with an influx of immigrants, and an increase in the poor (Brockett, 1855). This brought about a shift away from a model that provided hope to those less fortunate, to a model more reflective of power and control. In fact, the use of the term "model" became associated with the management of human behavior, whereby authority persisted over persons with intellectual disabilities (Wolfensberger, 1969; Sacks, 2009).

Another model provided power to physicians, who basing their knowledge on "hereditary, nervous diseases, or genetics" (Wolfensberger, 1969, p.2), would complete their diagnosis of the person. This diagnosis of specificity provided the physician with a rationale to consider a person for institutionalization. At the time, the only solution for a person with intellectual disabilities was institutionalization and segregation from society, based on a diagnosis that identified his or her as problematic to society or defective.

Alexander Johnson (1906) asserts that feeble-minded, deviant, or abnormal are unemployable, unable to contribute to society or to be respected citizens will have a negative influence on the economy, and could shift the current social order. However, if detained in a safe, segregated institution, administrators, medical personnel, and supervisors could maintain social order. Who defines the social role for persons with intellectual disabilities? Once we have definitions, does this automatically give permission to exercise control over those who are made powerless by an oppressive and expansive superstructure? Stiker refers to this implication as more "humanist and moral than social" (p.108), more like a rehabilitation approach; rise up be restored. The basis of the revolution model where the "proletariat worker and every poor person with him will become the object of charitable attention in order to get him to accept (if possible) the ways of the dominant group" (p.108). Freire (1973) asserts that "the oppressed are emotionally dependent" and "attempting to liberate the oppressed without reflective participation in the act of liberation is to treat them as objects which must be saved from a burning building; it is to lead them into the populist pitfall and transform them into the masses which can be manipulated" (p.65).

### Justification for the institutional model.

Alexander Johnson (1906) was the past president of the organization known as National Conference on Charities and Corrections, and the American Association on Mental Deficiency (AAMD). In a speech to the AAMD, he strongly opposes the rights of individuals medically diagnosed as feeble-minded, epileptic, or defective to have children. This philosophical belief came from the following hypothetical story he relayed to his colleagues in the anticipation all would agree this population of people not only need to be segregated from society, but "permanently detained at an institution" (p.2). Prior to the 1820's institutions were unseen across the United States landscape, criminals were jailed, persons with disabilities, especially those considered mentally ill, or retarded, were taken care of by family. The Jacksonian era reformers viewed crime and insanity as outgrowths of a diseased social order.

Johnson describes a father whose son was not demonstrating the necessary developmental milestones and the need to discuss with the family the delicate issue and the most appropriate steps to follow in order to institutionalize the son. Johnson proceeds to describe how the family is not ready to admit to the problem or reconcile with the belief that their son would not become a productive citizen. He continues suggesting that professionals know “in all probability, the child will never develop so it is wise and to the best interests of the child, of the family or of society, never to discharge him from your institution” (p.1). Johnson urged his fellow colleagues to reflect on how the feeble-minded are viewed, as someone to love, a drain on the economy, a subject for scientific research or a menace to society. Johnson argues for specialists to abandon the idea of education for the feeble-minded.

Wolfensberger (1969) indicates a peak growth of institutions, number of clients and per capita costs between 1908 and 1912, due to immigration and the development of intelligence tests. The historical aspects of Johnson’s beliefs developed during the height of immigration to America. Social and economic issues and problems did exist before the influx, however attitudes, values and beliefs greatly influenced the views of those who appear, think, or act different; society wants to place them away, make them invisible, or isolate or destroy their spirit.

### Immigration, IQ tests, and reform.

In the article, *Idiots and Institutions for their Training* (Brockett ,1855) , the building of schools or institutions were a way to promote the moral laws, to educate and train so the physical health of the idiot would improve, while negative behavior and habits would decrease. These attempts to accomplish these noble efforts “moral heroism, philanthropic, and religious gestures” were ways in which one could enter the gates of heaven. Social class became more prevalent, during the increase of immigrants arriving from Europe, who dressed differently, looked differently spoke with an accent, practiced different traditions, and who were forced to live in very poor areas. Many of their ways were considered inappropriate moral behavior and this led to greater and to more diagnoses of idiocy. Many thought alcohol consumption by the parents to be a direct influence on their children, who had the label of idiot. A new classification for idiocy developed because the majority social class believed the moral laws were decreasing and so was the majority race. Many believers thought this undesirable class of people would just go away because the laws existed (pp.7, 67).

What historical information provides the necessary connection between eugenics, immigrants, and links to current trends in testing and the exclusionary practices of ethnic groups? Has social culture moved forward in acceptance of others or do we continue to practice what history has taught us?  Danziger (1998) refers to the psychological testing process as a practice to control groups of subjects by controlling their performance. This science wanted to use treatment groups in practical yet “exemplary quality” (p.116). “Transferring their use to the laboratory allows one to construct a model of the kind of world that the laws of this new science presuppose. It is a world, in which individuals are stripped of their identity and their historical existence to become vehicles for the operation of totally abstract laws of behavior” (Danziger, 1998, p.116).

Ellis Island, a small parcel of land in New York harbor, was the gateway to dreams, opportunity, hope, and disappointment for many immigrants from many lands. What might have been the emotions of those arriving for the first time, seeing the spectacular Lady Liberty, who looks out on the world, without judgment? Would all their wishes come true or would many become disenchanted or deported? For many their reality was to arrive, only to be deported due to requirements set forth in an immigration law; determining which people were of “inferior stock”.

Francis Galton (1904) used the term eugenics in reference to the quality of physical and intellectual capacities, of persons who did not fit the dominant group. The Public Health Service and physicians were the first to practice methods of reducing the numbers of immigrants entering the country. Medical and mental testing was administered to all entering via Ellis Island. The eugenics movement seemed to justify the use of mental testing. The results of these tests demonstrated how the dominant social group in America began to use them for exclusionary and medical model purposes in the identification of immigrants as inferior stock, the promotion of stereotypes and stigmatization. Goffman (1963) expresses, “we construct a stigma-theory, an ideology to explain his inferiority and account for the danger he represents, sometimes rationalizing an animosity based on other differences” (p.5).

To initiate the discussion for limiting immigration, Galton (1904) presented a paper to the Sociological Society, at the School for Economics, London University, on the topic of eugenics, the definition, and purpose. He clearly makes reference to eugenics being a science “which will deal with all influences that improve the inborn qualities of a race and the improvement of the inborn qualities or stock” (Galton, 1904, p.1). Galton outlined, very specifically, the outcome of eugenics in relation to the best specimens. Galton wanted the Society to be the main organization to promote the tenets of eugenics. These tenets included knowledge of the laws of heredity; inquiry of a historical sort on various classes of society and contribution to the population; a systematic way of collecting data on the conditions of thriving and large families; influences affecting marriage, and “persistence in putting forth the national importance of eugenics” (p.2). Galton ended his presentation with recapping the first and main point “to secure the general intellectual acceptance of eugenics as a hopeful and most important study. Then, let the principles work their way into the heart of the nation…” (p.2).

The elite group of members present, among them, G.Bernard Shaw, H.G.Wells, Lady Welby, C.S. Loch and others, debated the good and the evil aspects of selective breeding, continuing bloodlines, and creating a society of intellectuals, while eradicating those under the category of inferior humans. Members debated aspects of political, societal, and religious areas, however, failing to resolve any of the arguments for or against, which disappointed Galton, who was "extremely unhappy with the quality of this debate" (p.4).

These preeminent members of the Sociological society may have been fearful and lacked knowledge of those arriving on these pristine shores, in search of what the members had, homes, clothing, jobs etc. In Galton's reference to the political agenda all pointed to establishing and expanding the immigration law;

> Congress passed America's first naturalization law in 1790. It limited the privilege of US citizenship to "free white persons". This law continued to be updated and expanded to include (or should we say exclude) "persons unable to care for himself or herself without becoming a public charge". With expansion of the law from 1790-1890 exclusionary factors continued to exist to include; convicted criminals, the poor, and the mentally ill; and the Chinese Exclusion Act of 1882, specifically exclude those of race and ethnicity.
> (Lombardo, retrieved 11/18/2007)

Young's (1922) research on immigration, provided the following significant comments: "a) the need for public opinion to change in regards to the desirability of immigrants; b) immigration needs to be controlled in the interest of the nation's welfare; and a "well worked out set of psychological and physical tests need to be applied for entrance into this country" (p.433).

Henry Goddard (1927) was also a pioneer in the field of eugenics. He professes a theory of inheritability of intelligence, as shown by his study of the Kallikak Family (1912). Goddard adopted the Binet tests of measurement as the instrument of choice, especially for those entering through Ellis Island. He had a peculiar way of demonstrating who was to stay and who would be deported. Goddard enlisted two women to conduct the "mental testing". The first step was to select an immigrant who looked “feebleminded by sight” who was then directed to the other assistant for testing, which was conducted in English (Kluth & Taylor, 2006). Many ethnic groups were determined to be feeble, such as Italians, Jews, and Hungarians. Kluth & Taylor (2006) report that Goddard “appeared to ignore the possibility that the low scores could be due to the fact that many did not know English or that most if not all were unfamiliar with the cultural norms reflected in the test items” (p.1). From this observation and testing method Goddard concluded that other countries were sending their most unsuitable and defective citizens to America. Data showed based on this information, in 1913, deportation increased dramatically (Kluth & Taylor, 2006).

In a study, conducted by Kimball Young (1922) on beta and alpha testing with Italians, Polish and Greek who were originally administered the alpha test, in English, were re-administered the beta with the final data reported “85% of Italians, more than 80% Polish and 75% Greek “ were considered inferior. The same method administered to Southern and Northern Negro draftees indicating 82% were inferior. This data was the first to indicate racism in ethnic groups. Another study conducted by Murdoch (as cited in Young, 1922) compared “500 Jewish, American, and Italian boys and 225 Negro boys. The results maintained the Italians and Negroes to be “decidedly inferior” to the Jews and Americans. Young (1922) examined the intelligence testing data of first graders in California public schools, of Spanish and Portuguese descent in comparison to Northern European and American. The Spanish and Portuguese ranked lower than the latter groups. Again, the study did not take into consideration cultural traditions or language.

In 1917, Congress passed an expansion to the current immigration law to include “all idiots, imbeciles, feebleminded persons, epileptics, and insane people…..persons of constitutional psychopathic inferiority…and mentally and physically defective and later to include immigrant groups as defined by the involvement of eugenicists". The new law based on this restriction ended an era of the largest number of immigrants to enter the US. The number of immigrants went down 15 percent from a 45 percent high. This restriction continued until the 1965 Immigration and Naturalization Act.

### New Era for institutional care.

Today terminology is changing to reflect a division in delivery of care. These models continue today, based on those which parties "initiate, influence, shape and order decisions" (Daley, n.d. p.564), such as doctors, lawyers, judges, professors, administrators, policy leaders and politicians. Mitchell, (1997) states the "disabled populations are linguistically transformed by a value-laden designation that determined their placement within a pre-ordained social order" (p.xii).

A system of health care afforded those with the finances to seek out qualified care while the poor are relegated to the often inadequate, mismanaged, and inefficient public system (Vachula, 1988). Foucault (1973) states, "the medical perception must be directed neither to series or groups; it must be structured as a look through the magnifying glass, which when applied to different parts of an object, makes one notice other parts that one would not otherwise perceive, thus initiating the endless task of understanding the individual" (p.15).

According to Braddock and Hemp (2008) "the nation's intellectual and developmentally disabled population peaked at 194,650, in 1967 which created a new response and call for construction of smaller modern state residential facilities" (p.6). No longer were these utopian institutions revered as the model of society, but became massive and overcrowded. Those who were viewed as deviant and dependent were controlled, leading to abuse and neglect by those in charge. Felton & Shin (1981) suggest that society regards those with disabilities as negative except within treatment goals. Policy and research become the constructive force for ideology, only to distort common perceptions of practice.

In 1990, the historic landmark American with Disabilities Act (ADA) became law. The ADA provides for the protection and rights to individuals with disabilities. The ADA provision for integration into communities, employment, transportation and other areas of community life, was a beacon of light for social justice. However, it has become a law, which is "failing to achieve demonstrable evidence of its successful implementation" (Mitchell, 1997, p.xiii). This legislation emphasizes community and participation when in fact it is providing lip service to those who wish for true equality among others. The American with Disabilities Act (ADA), Section II applies to programs, services and the public agencies that make provisions for the disabled. Under this section of the ADA, the courts became intertwined with the legal and foundational interpretations of making changes that may "fundamentally alter" its programs or services. Under Title II of the Act, public entities are required to make "reasonable modifications" to their programs to avoid discrimination on the basis of disability and to offer their services in the "most integrated setting" appropriate for the individual's needs. Title II of the Act, also states "unnecessary institutional segregation of the disabled constitutes discrimination per se which cannot be justified by a lack of funding". This Act and its criteria set by law provide the backdrop to my original purpose to understand the implications of the Olmstead Act on deinstitutionalization in the United States.

### History of Olmstead Case: Lois Curtis and Elaine Wilson.

According to Decker (2003) in the document entitled, *Olmstead v L.C. & E.W.: The story of the Olmstead decision*, Lois Curtis is a charming young woman, with a winning smile and personality to go with it. Lois' life has consisted of many difficult events due to her cognitive disability and mental illness. She grew up in public housing overshadowed by the large walls of a state penitentiary. These walls were to be reminders to her of the meaning of institutions. Lois' immediate and extended family loved and cared for her, even during times of violence in her neighborhood and own home. Lois was twelve years old before the diagnosis of severe mental disabilities, etiology and date are unclear.

After Lois was deemed unsuccessful in public school, she rode the bus to a psycho-educational center. This facility was designed to educate students diagnosed with severe emotional and behavioral disabilities. Even though Lois learned to ride the bus, she did not enjoy being away from her family, friends, and community; these experiences caused her behavior to escalate. This educational experience did not last long, however. She was sent miles away from her family, to an institution with 400 residents with disabilities. This institution would be the first of many for Lois. By the time Lois was twenty she had spent half her life in segregated and congregated places for the disabled.

Lois became accustomed to living in and out of public and private nursing homes, institutions, care/boarding facilities, and hospitals. No matter where she lived, she knew her family loved her. Her mother taught her how to sew; her grandmother taught her how to cook, clean, and care for a home. Lois' dream was to live in an apartment or home of her own "somewhere near her family, and where people understood and respected her as a person" (Decker, 2003, p.10).

At 22 years old, Lois was still not receiving support services to help her live in the community near her family. Many did not understand Lois' need to be near her family. Lois was able to access an apartment however, the lack of supportive community services and her history of troubled behavior made living in the community impossible for Lois (Decker, 2003). Soon

Lois would act out again with the consequence of returning to the institution or hospital to be locked away and isolated. Many large facilities were not sensitive to Lois' need to contact her family or be interactive with peers to form friendships.

Lois' would become overwhelmed because of the lack of stimulating activities and the confinement. She was lonely, even though she had adapted to the rigid structure of the institution. These immense feelings were hard on Lois and she began to chain smoke as a way to sooth and comfort herself. Alternatively, she would pick up the phone to call Sue Jamieson at Atlanta Legal Aid. People who are institutionalized for long periods of time (Decker, 2003) do not typically possess these interpersonal skills. Lois had a unique and uncommon sense of self-advocacy that allowed her to make meaning of a useful, fulfilling life outside the institution.

Others with disabilities looked upon Lois, as a civil rights activist, leader in the disability rights movement. Others saw Lois as having "behavioral problems which must be managed" (Decker, 2003, p. 11). Decker (2003) states if Lois or others within the walls of an institution had demonstrated acts of defiance or resistance, most likely, they would be restrained, medicated or both, as this is life in the institution. Lois did not sit back; she continued to struggle until her cries for help were heard. And heard they were, for her persistence led to one of the most important pieces of legislation since Brown v the Board of Education and the Civil Rights Act of 1964 (Decker, 2003; Brazelon Center, 1999; Bagenstos (2009).

Lois Curtis had been in contact with Sue Jamieson for many years, while living in an institution. Sue continued to work with the Department of Human Services, in Georgia only to be consistently told there are no openings anywhere. Sue tried to negotiate a plan for supports to house Lois in the community only to refused again. Sue saw Lois' situation becoming more desperate with Lois' continuous smoking, lack of friends, increased loneliness, and general unhappiness. Sue knew now that something needed to be done for Lois and others who were in these places of isolation (Decker, 2003). Sue soon met with Elaine Wilson as she continued to find a solution to Lois' situation.

**Elaine Wilson.**

According to Decker (2003), Elaine Wilson's story begins with the onset of polio or a similar serious illness that prevented Elaine from meeting her developmental milestones. Elaine's mother decided to take her daughter to a psychologist upon entering school. The psychologist diagnosed Elaine with brain damage. The psychologist told her mother she would never be like the other children, so Elaine was institutionalized.

Elaine's mother took her daughter home and taught her during the early childhood years, while looking for the best and right schools for Elaine. This was not easy to do in the 60's, as there were very few programs in existence to educate children with disabilities. When Elaine turned fifteen years old, her mother enrolled her in the Gracewood State School and Hospital in Augusta, Georgia. Again, the doctors re-evaluated Elaine, produced the same diagnosis of mental retardation and recommended she be institutionalized. This was the only resource available to meet Elaine's needs.

Elaine did not enjoy being in this place because she was not challenged and missed her family. Elaine grew more frustrated every day until she became rebellious and hostile and refused to behave. No one in the institution wanted to see the real person Elaine was someone with a charming personality who was outgoing. Elaine attended her first dance at Gracewood State School, which would be her last for a long time (Decker, 2003).

During the next fifteen years, Elaine was in and out of institutions, "[she received] shock treatment, was restrained, medicated and isolated in locked rooms that only contained a mattress" (Decker, p.14). The experience of institutionalization made Elaine feel bad about herself, as if she was a bad person and needed to be fixed, as if she were broken. By 1995, Elaine was once again admitted to Georgia Regional Hospital, with the likelihood of leaving only to be readmitted repeatedly. For Elaine this seemed to be a never-ending cycle of never knowing where she belonged.

### Filing the petition against Commissioner Olmstead.

In 1995, Sue Jamieson filed a case with the United States District Court for the Northern District of Georgia, against commissioner Tommy Olmstead, of the Georgia Department of Human Resources, the Superintendent of Georgia Regional Hospital, and the Executive Director of the Fulton County, where Lois and Elaine's civil rights were violated as appropriately cited in the Americans with Disabilities Act, Title II.

Title II of the Act provides:

> Subject to the provisions of this subchapter, no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of the public entity, or be subjected to discrimination by any such entity. (ADA, 104 Stat.337, 42 U.S.C. 12132)

Lois and Elaine won the first case, however the State of Georgia appealed to the next level of jurisdiction, claiming first it had not discriminated and that providing additional state funds would fundamentally alter its activities (Decker, 2003). The Courts disagreed and found Lois and Elaine had a right to appropriate services that would enable them to live in the community. The case was appealed a third time, this time going to the Eleventh District of the Supreme Court. The final stage was the ruling from the Supreme Court, June 22,1999 stating,

> This case concerns the proper construction of the anti-discrimination provision contained in the public services portion (Title II) of the American with Disabilities Actof 1990, 104 Stat. 337, 42 U.S. C. 12132. Specifically, we confront the question whether the

> proscription of discrimination may require placement of persons with mental disabilities in community settings rather than in institutions. The answer, we hold, is a qualified yes.
>
> …In so ruling, we affirm the decision of the Eleventh Circuit…..
> ___U. S. ___1999.

In 2009, Olmstead celebrated its 10th anniversary, however, without much fanfare. Today, many states fail to comply with Olmstead and have not developed a working plan for delivering services and programs, within the parameters of the law. The Justice Department is aware of states not in compliance and has stated it will "invigorate their enforcement of Olmstead", to reach the level of its historic promise. The promise for the following year, 2010, is to aggressively, enforce the law in the states by filing amicus briefs in order to move forward in many of the unsettled areas that remain open after the Supreme Court's decision, ten years ago. Under the Civil Rights of Institutionalized Persons Act (CRIPA), federal lawyers can act on litigations outstanding; however, the parameters for inappropriate conditions and appropriate settings remain.

## Deinstitutionalization: Reality or Lip Service?

In a report entitled Deinstitutionalization: Georgia's progress in developing and implementing an "Effective working plan" as required by Olmstead v L.C., et al.", Tidwell (2009) comments on the lack of a necessary effective working plan for the State of Georgia, as ordered by the Supreme Court, in 1999. Like many other states, Georgia continues to fail to comply. There is a "tongue in cheek" reference made by some, in the judicial arena, that the State of Georgia being the Olmstead state. In addition, it is a necessity for the state to be a leader in the area of compliance to implement a plan to support people with disabilities, (who meet the criteria), to live in the community of choice. Tidwell (2009) states that, the plan for deinstitutionalization must account for the provision of supports and services that enable a person to achieve a safe and productive life in the community. This plan was to detail how the state was to achieve making reasonable accommodations, not to restructure the state's system of care. How to address the wait list and effective planning were left unanswered by the Supreme Court.

The Ninth Circuit Court did address three areas in which the state would need to demonstrate significant progress made by 1.) Moving people out of the institutions 2.) Increasing the budget for community services in spite of fiscal constraints and 3.) Increasing the size of the Home and Community Based Services (HCBS) waiver program over time. The caveat to the above is the state did not need to provide a written plan for how to achieve these goals. For example, there was no mandate to demonstrate how to move a specific number of people out of the institutions only to demonstrate progress in each of the areas.

The Third Circuit Court addressed its support for states to demonstrate a past commitment to deinstitutionalization, and require that a plan demonstrate specific measurable goals and be held accountable. Georgia did proceed right after this decision, by creating a Blue Ribbon Task Force (BRTF), in December 1999. The BRTF was composed of parents, advocates, consumers, and other professionals, 17 members in all. The task force was to develop a strategic plan, to gather information and report to the Governor, and state legislature in January 2001. The charge was " [to determine] status of and future need for community services in Georgia; to identify barriers that prevent access to services; to make funding recommendations; to give advice on how to prioritize services; and to identify possible waiting list criteria" (p.714).

The State of Georgia received a grant from the Center on Health Care Strategies to develop a plan, which led to the creation of the Olmstead Planning Committee to meet eight times, from February to October 2001, in an effort to provide a developed plan for providing services within the compliance of the ADA and Olmstead decision (Tidwell, 2009). The final report was completed in November of 2001, giving extensive recommendations for moving people out of institutions by a certain date; increasing the system capacity in communities; providing action steps for agencies responsible for each item; mandating infrastructure improvements to the areas of housing and transportation; service expansion; provider development; and workforce development (Tidwell, 2009). The Governor would not make a commitment to implementing any of the committee's recommendations therefore; no formal plan was developed or submitted.

According to Tidwell (2009), two years later, another Governor set in motion another committee to review and modify the original Olmstead plan, but without measurable outcomes or target dates and no mechanism for accountability. This document became one of intent only. This plan called for the identification of individuals in state hospitals, nursing homes, and those at risk for institutionalization; an evaluation of individuals to assess the benefit of community; and assessments to continue while the individual was in the community (Tidwell, 2009). The purpose of the assessments was to evaluate the wait list in a timely manner. All this appears within the scope of progress however, no mention was made of which agency would be in charge of the content or conducting of the assessments or any additional or subsequent evaluations.

There was no effort to update a plan until 2008 when Georgia entered into a settlement agreement with the U.S. Department of Health and Human Services Office of Civil Rights. Under this agreement, by February 2009, Georgia was to submit another plan stipulating concrete and realistic, annual Olmstead goals, with a report every December to the committee on the progress of implementation. The State of Georgia's progress in moving people out of institutions, developing a waiver program and increasing spending on community-based services may have met the Ninth Circuit Court's requirements for an effective plan. However, Tidwell (2009) cautions the State not to allow the fiscal constraints to "impede its progress in the future" (p.731).

### **Supreme Court Olmstead decision.**

In 1990, Congress made sure to describe the isolation and segregation of persons with disabilities as a serious and pervasive form of discrimination, this was included in the Americans with Disabilities Act (42 U.S.C. 12101 (a) (2), (5). Title II, which proscribes discrimination in the provision of public services, specifies, that no qualified individual with a disability shall because of such disability, be excluded from participation in, or be denied the benefits of, a public entity's services, programs, or activities (p.581-12132).

Justice Ginsburg delivered the opinion of the Court, joined by Justice O'Connor, Justice Souter, and Justice Beyer concluding under Title II of the ADA, "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" (p.582). The person with a disability must deem the transfer from one institution to a community placement beneficial, the accommodations must be deemed "reasonable" by taking into account the available resources of the State and the needs of others with disabilities.

The Court's opinion stipulated that the ADA not to be interpreted as urging States to phase out all institutions or placing those at risk for harm in the community. Nor, is it appropriate to have States move persons from one institution to an inappropriate placement such as a homeless shelter. The Attorney General's regulations issued two key determinations regarding integration and reasonable modifications. (1) Unjustified placement or retention of persons in institutions severely limits their exposure to the outside community, and therefore constitutes a form of discrimination based on disability prohibited by Title II, and (2) qualifying their obligation to avoid unjustified isolation of individuals with disabilities. States can resist modifications that would fundamentally alter the nature of their services and programs. Segregation is unjustified when a person is capable of living within the community and can benefit by this interaction. However, a person's isolation can foster the assumption that a person is incapable or unworthy of participating in the community (p.527 US 581 1999).

### Promises kept or unfulfilled.

Some states followed what Congress stated in the ADA findings and the Medicaid statute, that "reflect a congressional policy preference for treatment in the institutions over treatment in the community" (p.527 U.S. 581 1999). Since 1981, Medicaid has provided for state run home and community based care through the waiver program. The Department of Health and Human Services (DHHS) allocates waiver slots to states, but states do not always use them; such is the case with Georgia. In 1996, DHHS allocated 2,109 waiver slots, but Georgia only used 700 (p.527 U.S. 581 1999). In conducting a literature review, the topic of Medicaid waiver is consistently associated with the discussion of institution and de-institutionalization options. This may influence how delivery of services is provided to individuals within the community or the extent to which individuals gain independence to make their choices. Ironically, the disabled still need to qualify for community services (Tietelbaum, Burke, and Rosenbaum, 2004).

The National Goals for Persons with Disabilities (2000) included an explicit promise of integration, community living, inclusive schooling, employment, and opportunities for total participation. Freedom, citizenship, and participation are its important components as opposed to cost, the benchmark for service organizations and institutions. The Olmstead decision can offer context for understanding the National Goals. However, the impact is still on how to access or advocate for the necessary support and services, once an individual is deemed qualified to move from the institution into the community. In his concurring opinion, Justice Kennedy, raised some concerns about the Olmstead Act, warning, “the depopulation of state mental hospitals has its dark side” 527 U.S. 581 (1999). Kennedy cautions states who may react to fear of litigation by placing those individuals who are considered to have marginal needs, into a placement lacking adequate services. The additional danger is in the concept of federalism (States ability to function without undue federal interference). Kennedy continued to express constitutional concerns regarding the “federal courts being given the authority to review the states choice in basic matters such as establishing or declining to establish new programs” (McCants, n.d. p.283).

**Summary.**

Bagenstos (2009) provided remarks on the 20th anniversary of the Americans with Disabilities Act, arguing for the necessary involvement of the Department of Justice. His comments revolved around the inequities and unequal chances for those with disabilities to live a life of choice. Bagenstos comments include the Olmstead decision as the Brown v Board of Education of the disability rights movement. The core of Olmstead is the right for individuals with disabilities to choose where to live in the world. He reiterated 20 years of ADA legislation have provided the fundamental right to live in the world, making good on the Constitution’s promise of equal citizenship and the Fourteenth Amendment guaranteeing equal protection of the laws, for people with disabilities. Bagenstos (2009) continues that the rights of persons with intellectual disabilities are to live their life with basic services and confinement to institutional settings is an inappropriate placement based on the lack of appropriate funding. One such setting referenced was that of the large institution known as Pennhurst, which at one time housed 3,000 people. Bagenstos (2009) refers to a pattern of marginalization as people being shut out, pushed aside, and ignored, because of fear or benevolent charity, and shared destiny to live in out of the way places, far from family and community

Today, people with disabilities, especiallty in Illinois, face inadequate funding, lack of employment and choices, which prevents access to community citizenship and supports placement in nursing homes and other segegrated facilities. When we segregate people with disabilities from the community, we deny them the right to live in the world.

# Chapter Four

## Illinois and a wayward system of care

In this chapter, I begin a historical journey to define my study of deinstitutionalization and overall impact on people with disabilities, especially in the state of Illinois. Deinstitutionalization is a term which conjures up visions of people leaving state facilities, en masse, roaming aimlessly in the community, going back to their families, who may be unprepared for their loved ones arrival, or becoming homeless and living on the street. In contrast, however deinstitutionalization means the movement from a group of services, within a system of control and care, to service provision based on an individual’s choice of independence in the community. The concept and ideology of deinstitutionalization reality turned into a form of capitalism via Medicaid funding for the provision of supports necessary for success, in community living. The reality of deinstitutionalization was no provision of community support (i.e. financial, social or political) services for many people with disabilities.

### Institutional rise in the State of Illinois.

The construction of the Dunning Asylum began in 1859 and cost the State of Illinois $25,000. Over the years, the peak patient population was 2,100 by 1955. Chicago State Hospital, aka Dunning, later known as the Chicago-Read Mental Health Center, originally sat on 40 acres. Dunning was home to patients who lived, worked and died behind the eight-foot iron picket fence, many sick, incurable, and in need of long-term hospitalization. The state demolished the original facility in 1980 (Kelly, 2009).

Today, the land is a very little park called Read-Dunning. Within the park lies a concrete circle attached to a sidewalk and a not so fancy iron arch bearing its name. Once going beyond the arch, is a plaque memorializing Cook county’s potter’s field cemetery, where the unknown burial plots exist. According to Kelly (2009) the historical records indicate 38,000 people are buried in the potters field; no names, just numbers. There is a large concrete circle which is the marker labeling some as unfortunate, sick and infirmed, orphaned/abandoned children, and insane. Many issues plagued Dunning, which are similar today, including the lack of qualified physicians, lack of money, overcrowded facilities and poor follow up care.

### Lincoln Developmental Center.

The State of Illinois General Assembly charged the Illinois Institution for the Education of the Deaf and Dumb to build a facility, which for the purpose of instruction and training idiots and the feeble-minded. In 1875, the school name changed to the Illinois Institution for the Education of Feeble-Minded children. The name changed in 1877 to the Illinois Asylum for Feeble-Minded Children. The institution was located in Lincoln, Illinois. The architects designed a cottage plan, which included its own hospital, shops, where inmates made mattresses, brushes and shoes. There was a farm, which the institution owned, where the inmates also worked the land.

In 1909, the State Board of Commissioners of Public Charities was disbanded and abolished. The executive administrative control went to a newly created Board of Administration. This board changed the name to the Lincoln State School and Colony, only to change many years later to the Lincoln Developmental Center. The continuation of detail and research on this facility will be included in the analysis of policy, because the Lincoln Developmental Center has a significant history to the area of deinstitutionalization and the Olmstead Law. This will be explored further during the final research components.

### The system of mental health and deinstitutionalization another perspective.

The deinstitutionalization movement began with President John F. Kennedy's call to action, in 1963, to begin to reduce the number of persons who resided in institutions and return them to their communities with necessary services (Longmore, 2002). This began the movement out of the large congregate institutions, however many went into smaller group homes, nursing facilities or leaving some homeless. Bogdan and Taylor (1990), coined the term "trans-institutionalization" meaning, "the transfer of people from large public institutions to somewhat smaller ones in the community or leaving people to fend for themselves on the streets…. to board and care facilities that are as segregated from the larger community as the public institution from which they came" (p. 184).

Mechanic & Rochefort (1990) offer another perspective on the topic of deinstitutionalization and reform. They discuss comparisons of states in their dependence on their structures of the health system and support. They refer to this as "strength of the mental health system" (p.314) due to the power base, social and economic factors. Mechanic & Rochefort (1990) state the movement created in the 1980's gained momentum due to the 60's and 70's social policies of Medicaid, Social Security Insurance (SSI) and Social Security Disability Insurance (SSDI), housing programs and food stamps, which provided people with disabilities necessary programs for subsistence. As the population increased, growth in the provision of programs and services decreased. The cutbacks in social service programs throughout the country stalled in providing necessary supports to people with disabilities so they could live in the community, access to employment in order to stay afloat, from becoming one with an increasing population of homeless and poverty-stricken groups (Mechanic & Rochefort 1990).

According to Mechanic & Rochefort (1990), in order for deinstitutionalization to become successful, suitable housing needs to become a reality not the barrier it continues to demonstrate. One of the barriers appears to be in the discharge plans of people with disabilities, based on the professional deemed qualified to sign off and permit the person with disabilities to leave the institution, to live in the community successfully. This professional has the assigned role of making the decisions of who goes and who stays in the institution, based on their professional judgment. For some, the philosophical belief is that persons with ID/DD cannot be supported in the commnuinty. Since the mid 1970's, there has been a decrease in persons living in institutions, for example, institutions peaked in 1967 to 194,650 and went down to 24,708 (Shoultz,et al, 2005; Larson & Lakin, 2002). A point for consideration is in Illinois the number of residents living in nursing homes was 71,085 (Larson & Lakin, 2002).

The economics of deinstitutionalization continues to be at the seat of the ongoing debate of where a person with disabilities can live. The provision of case management services is an effort to advocate for the person to live within the community with necessary supports and services. Some of the difficulties faced by persons with disabilities, because of significant medical, behavioral, psychiatric needs, or those who have grown old in the institution, might be lessened if the concept of money follows the person could be utilized appropriately and efficiently (Shoultz, Walter, & Taylor, 2005). These ongoing reasons reflects two trends in making a move from institution to community however, the cost of supporting individuals in institutions continues to be forefront. Another challenge is from the community and employee unions because of the financial loss of closing an institution (Shoultz et.al, 2005).

According to a 2004 report by Equip for Equality, "Money Follows the Person" programs are used in many states to ensure that people live in settings of their choice and have flexibility and control over available resources for long-term community supports. States successful in community integration have aggressively utilized all or most Medicaid options. In some cases, budgetary limitations have constricted states' capacities to increase their matching funds, with the result that some states are not fully maximizing their Medicaid dollars" (p.6).

Equip for Equality (2004) continues the argument for community inclusion by stating,

> Litigation continues to be among the strategies used to require states to cease alleged violations of federal Medicaid law, the ADA, Section 504 of the Rehabilitation Act, and the U.S. Constitution. Litigation has been successful in improving access to Medicaid home and community services, decreasing waiting lists for community placement for institutionalized people, downsizing institutions, and challenging restrictions on the scope of services so that individuals with developmental disabilities can live in the most integrated settings. (p.6)

Mechanic & Rochefort (1990) indicate three areas of improvement for the system of support services, case management, capitation (refers to a set amount of money designated for services which are predetermined), and development of public mental health authorities. Mechanic and Rochefort, (1990) state, "Thirty-five years of deinstitutionalization and the growth of a broad range of services have resulted in a decentralized, pluralistic mental health sector funded by a diversity of public and private programs" (p.322). A possible interpretation of funding to a diverse group of public and private programs can create another layer for persons with disabilities to navigate, in which case management needs to justify allocated funding for the person. Creating another maze of services for persons with disabilities and families becomes exhausting and frustrating, and can lead to a lack of quality services within the community and possible re-institutionalization. There are larger social issues regarding deinstitutionalization, the political climate, the lack of support for a mental health system (on the verge of being deemed unwell), implementation difficulties which has neglected to endure a positive relationship between community and state hospitals and an unfulfilled promise of equal opportunity provided by law.

During the 1970'and 1980's, the Illinois political system's patronage created an interdependent relationship between officials and institutions. These political allies had a mechanism in place and the closing of institutions would require the loss of political power (Parish, 2005). As I continue to research and analyze documents related to Illinois policy, the intent is to discover a need for a consistent policy framework for developing protections and supports to the disabled to make the "rhetoric of deinstitutionalization less a dream and more of a reality" (Mechanic and Rochefort, p. 324).

The history of institutional life remains a topic of debate, resolution, and progress. However, Bredberg (1999) suggests it would be wise to follow critical analysis of the topic written with the perspective of one who has lived this life. She refers to the invisibility of people with disabilities, who are written about in various roles from that of "recipient of institutional practice" (p.199) to one of a much broader topic of the "personal and active presence in history" (p.199), which will contribute to more of a "parallel sense of involvement in the present" (p.199). In other words, writing the story as, told by the person with a disability, with the experience of living in an institution. I am in support of Bredberg, however some do not share the same thoughts or beliefs. If I am to research and write within the framework of lived experience, my story needs to include those with opposing views to this debate.

In the State of Illinois, the organization known as the Voice of the Retarded (VOR) played a significant role in opposing the closing of many state facilities, as well as opposition to the Olmstead Act. The VOR tenets follow the ideology that persons with disabilities need protection from the outside world. They need the institution for safety and medical services, which group homes may not provide to individuals with severe disabilities. This group of family members and some politicians believe advocates for deinstitutionalization are “mesmerized by the mystique that all institutions are bad, that the buildings be razed, the earth bulldozed over and then salt poured on the grounds so it never rise again” (Edward Walen, parent, 1995). This comment reflects the fear many families have for their sons or daughters with severe disabilities, including the advanced age of their children and themselves. In order for this research to reflect the opposition to this debate, especially in Illinois, I may need to find the voice of those who see institutionalization as necessary.

### ADA and Olmstead-The new era.

In 1990, President Bush signed into law, the historic landmark American with Disabilities Act (ADA) that provides for protection and rights to individuals with disabilities. The ADA provision for integration into employment, transportation and the many various areas of community life became the beacon of light for social justice. The ADA known as the Civil Rights Act of 1990, however, has become a law that is “failing to achieve demonstrable evidence of its successful implementation” (Mitchell, 1997, p.xiii). This legislation emphasizes community integration and participation when in fact it is providing lip service to those who wish for true equality among others. For example, in higher education students with disabilities need to provide documentation of their disability as justification for necessary accommodations. Persons with disabilities seeking state services need to provide documentation, because the law reads equality, however in reality proof is needed.

The American with Disabilities Act (ADA), Section II applies to programs, services and the public agencies, which make provisions for the disabled. Under this section of the ADA, the legal and foundational interpretations created an entanglement for the courts in the process of making changes, which may fundamentally alter programs or services. Under Title II of the Act, public entities are required to make “reasonable modifications” to their programs to avoid discrimination on the basis of disability and to offer their services in the “most integrated setting” appropriate for the individual’s needs. Title II of the Act states “unnecessary institutional segregation of the disabled constitutes discrimination per se which cannot be justified by a lack of funding”. This Act and its criteria set by law provide the backdrop to understand the implications of the Olmstead decision on deinstitutionalization in the State of Illinois.

The legislation of both the ADA and Olmstead specify for states to appraise, within the context of least restrictive environment or continuum of services model, the delivery and provision of services into community life to people with intellectual and developmental disabilities. The states need to view this legislation to their already existing structures, as a non-threatening issue, but to view this as an opportunity to change the stereotypes and stigma attached to those with disabilities. States receive federal money for services and programs established by the ADA, it is now up to the states to look to the future of “eliminating the legacy of segregation and integrate peoples with disabilities into the mainstream of American life” (29).

### State of Illinois and the Olmstead discussion.

The Supreme Court ruling of LC vs. Olmstead, in 1999, stipulated persons with disabilities the opportunity to choose where to live which includes supports for these services within their community. Illinois unfortunately continues to have one legal suit after another. As of 2011, Illinois has 13 legal cases against it for non-compliance of the Olmstead decision. In fact, Illinois does not have a compliant plan to meet the criteria as stipulated in the Olmstead decision. The Illinois Council on Developmental Disabilities proposed, in 2008, a Blueprint for

Change, which lays out specific areas for the right to community living and closure of state institutions. In 2011, Ligas v Maram a court ordered decision will bring into compliance the renderings of the 1999 Federal Olmstead decision and recognizes Title II of the Americans with Disabilities Act (ADA) that persons with disabilities have the choice to determine where and how they want to live in their community. Even though the Ligas v Maram decision has rendered choice and decisions for 3,000 class members, over the next nine years, the process to identifiy them will come from the Priority Utilization Needs System (PUNS). Identification of class members will include those on the wait list and people identified as in crisis, however , the reality for others in Illinois remains, who will benefit from this decree. There are still many customers/clients who wish to remain in their current situation or have declined the opportunities created by the Ligas Implementation plan.

The Olmstead decision appears to be one of insignificance for many states, which sends the continued message of persons with intellectual disabilities are not capable of making their own choices on where to live, work or socialize, especially choice of home. After centuries, of the less than normal message, states continue to use the same story of no money available for affordable or livable housing within communities of choice.

**Summary.**

The history of deinstitutionalization began with a paradigm shift stemmed from family members and persons with disabilities who wanted more choices, equality and equity in services. Wolfensberger (1969) developed such terms as normalization and social valorization to reflect changing perceptions of persons with intellectual/developmental disabilities who resided in institutions. The discovery of inhumane treatment of persons with disabilities became public when Burton Blatt (1985) provided photographs of the conditions in the institutions. Geraldo

Rivera’s television production of conditions in an institution  was the ripple effect many needed to begin to re-think institutionalizing versus closing these facilities down. Families wanted more for their children than putting them away because society viewed them as a burden and unfit for any productive life. Families wanted their children to be educated with their peers. In Berkely, Ed Roberts was setting the major stage for the Independent Living Movement by studying at the University of California, Berkley. He was a major force for what was to become the Disability Rights Movement (DRM), based on the principles and beliefs of the Civil Rights Movement. The DRM is responsible for the largest mass movement to pass laws such as the Rehabilitation Act of 1973 and the Americans with Disabilities Act 1990. People with disabilities were speaking out, becoming advocates to change a system, which had long neglected and made them invisible.

# Chapter Five

## Findings

The purpose of this study was to examine and analyze the historical connection between institutionalization, deinstitutionalization, and the connection to the Olmstead law, the Ligas Decree and the lack of an effective policy and plan, in the state of Illinois. This connection appears to have an impact on the social, political, economic, and lived experience of persons with intellectual disabilities and their families. The federal and state agencies, and a vast number of advocacy and community organizations continue to experience barriers and challenges. This chapter will address the following research questions, which were influenced by this study.

1. What are the historical underpinnings of inequity and marginalization of people with intellectual disabilities? What is the role of social and economic factors?
2. What is the historical connection between deinstitutionalization and the Olmstead decision? How does the historical connection between oppression, institutionalization, and the Olmstead decision currently affect the lived experience of persons with intellectual disabilities?
3. In what ways did persons with intellectual disabilities, advocates (pro and con), families/parents and other key stakeholders impact steps to make changes to institutional and community care, in the state of Illinois?
4. How might Olmstead policy affect future legal judgments in the state of Illinois?

### Data Analysis.

The data collected consisted of conducting a semi-structured interview with a Ligas litigant, a state advocacy organization member, a major suburban service provider, and the program coordinator of the agency designated by the Ligas Decree. I reviewed various legal documents, such as the Ligas Decree and Implementation plan, the Blueprint for Illinois, and the court monitor annual reports to provide understanding of policy development in the state.

Turnbull, Wilcox, Stowe, and Umbarger (2001) describe 18 core concepts associated with disability policy, which affect families who have children with disabilities, and each associates with a constitutional principle that aligns with a Supreme Court or other courts reference to the decisions made. Turnbull, et.al lists 18 core concepts however, for the study I chose to use only five core concepts,

In Stowe and Turnbull (2001), Tools for analyzing policy "on the books" and policy "on the streets" provides a novice a framework for interpreting and organizing information, while thinking about disability policy. The core concepts are defined as: (1) analyzing policy "on the books", which are court decisions, statutes, and other policy documents; (2) analyzing policy "on the street", which covers organizations and agencies; (3) determining whether a policy is appropriate to reflect one or more core concepts; and (4) connecting the core concepts to practice and then to quality of life outcomes for families.

This framework provides the foundation to ensure the process of validity of the personal narratives and documents and make connections to the themes associated with the lived experience. The summaries of the personal narratives provide context to similar themes associated with the research questions.

**Themes.**

The process used for analyzing, interpreting, and establishing validity of the data, consisted of reading policy reviews and newspaper articles for historical context. The clean copy of interview transcripts facilitated the process to identify emerging patterns or connections; similar or different themes to find meaning within a historical context and to provide understanding of the findings (Sherrod, n.d.). The documents related to the Ligas Decree, the Implementation Plan(s), a rebuttal from legal counsel and the Illinois Blueprint: Tipping Point (2012) were read and noted for the core concept categories. The coding process for the interviews followed the concepts as described in Stowe and Turnbull and consisted of highlighting relevant areas in order to connect with the core concept and research questions.

The data located in Table I Guidelines for analysis of data and research with Core Concepts chart labeled as, Relevant Items, Disability policy core concepts, and Comments/Themes. The relevant themes among the interviewees and documents appear to be similar in the areas of advocates having a voice in the active Ligas process, state funding, legal compliance, and development of a plan or policy associated with the requirements in the Olmstead law.

**Table I**

**Data source chart: Guideline for analysis of data and research with Core Concept**

| Relevant Items | Disability policy core concepts | Comments/Themes |
|---|---|---|
| Illinois Blueprint-Tipping Point; Ligas Decree Implementation Plan, Transition Plans, Monitor Reports. | 2. Individualized and appropriate services: services specifically tailored to meet the needs in addition, choices of persons with disabilities, and their families. | Choice and options; smaller ICF/DD to 4-6; funding options (Money Follows the person) State budget cuts. |
| Ligas Implementation Plan Revisions; Monitor Reports; Blueprint Tipping Point; Murray Family Association and closure of facilities. | 4. Capacity-based services: reflects a strength perspective and rejects a pathology approach to identification of services to enhance the individual or family capacity, concerns, resources, priorities, and choice. | Transition Planning; class member selection; waiting list eliminations; budget cuts; new litigation (6.30.15) for compliance with Ligas decree |
| Ligas Implementation Plan Department of Human Health Services webpage; Interviews with service providers and advocacy for the state; CQL and litigant interview. | 5. Empowerment/Participatory decision-making: decisions based on individual or family want from a service provider system, participation in planning developing, implementing, and evaluating decisions within the macro/system level and micro/ individual level. | Person-Centered planning; transition planning in western and southern part of state; numbers reduced per Ligas Decree and plan. |
| Ligas Implementation Plan; Court Monitor Reports Interviews | 9. Autonomy: the rights to consent, refuses consent, withdraw consent, or control or exercise choice over what happens to him/her, or if legally incompetent a duly appointed surrogate may do so. To be independent or exercise self-determination. | Reduce wait lists/crisis lists; choice and options for community-based services |
| Interviews; Ligas decree ADA; Olmstead Act. | 11. Integration: the right to not be segregated solely based disability. | Choice, reduce wait lists, closure of facilities; budget concerns. |

### Participant Narratives and Process.

The purpose of this study and research was to examine the lived experience through the historical lens of institutionalization and connect how the lack of an Olmstead plan continues to create barriers and gaps in state policy needed for deinstitutionalization and the provision of services for community choice for persons with intellectual disabilities. The following narrative interviews are derived from clean transcripts and provide an understanding of the litigants lived experience, expressions of success and challenges encountered by the providers and establish common themes and similar language necessary to establish connection to overarching research questions.

I sent an email to each participant explaining the interview process, purpose, and a copy of the Informed Consent Release document, as required by the university's IRRB committee. I developed a structured set of questions to be used as a guide and sent to each participant for reference. The informed consent explained that access to any recordings, transcripts, or field notes or other information provided during our interview would be confidential and not attached to the data and this was a voluntary process, which participants may discontinue at any time. We scheduled interview days and times via email. The interview conducted with DC was in person, including the presence of his parents.

Patton (1993) states the credibility and reliability of the source must be judged as well as with all types, "we may be seeking the interviewees view of an event or interpretation of a rule or regulation…..there may be no absolute truth." He continues, " the interview should not be the only source of information and the findings from the interview can be checked against the facts." (p.113).

**TP, CEO state advocacy organization.**

For the last twenty-three years, TP has been CEO of a major state advocacy organization, which serves persons with intellectual and developmental disabilities. TP continues to keep a pulse on all political, social, and economic issues facing persons with disabilities and their families. TP considers himself, a historian. I wanted to interview TP based on his long career with a state advocacy organization in Illinois. TP has provided self-advocates and their families with information and training needed to address current legislative concerns in the state. The interview with TP lasted for thirty minutes by phone from my office, during the month of February 2015. We had various scheduling issues prior to February 2015. TP's interview links to the core concepts of Empowerment and Autonomy.

TP expressed interest in participating in this interview, however at times I sensed some hesitation and guarded responses, especially when questioned about the political aspects associated with Ligas. TP was careful in choosing his answers without any indication of the state formulating a solid Olmstead plan. When asked about his agency's involvement in the initial legal suit,

> Well, we did provide some input as a stakeholder and we had a working relationship with the folks at Equip for Equality. And we have a strong working relationship with the court monitor, as well as, Equip for Equality. But there's….only as a stakeholder in this system. I have not standing…the Arc has no standing in this lawsuit.
>
> TP, transcript, 2015.

TP's position and the many responsibilities, within the broader political climate in Illinois provided an opportunity to discuss the election of a new governor. It appears there are different viewpoints associated with working with persons with disabilities. During the campaign for governor, the topic of closing state operated facilities was an emotional topic for many. TP discussed,

> Well, former governor, Pat Quinn, has closed no less than three state institutions in Illinois and that was….Governor Quinn called it a re-balancing initiative. And I think, in my opinion, his team put together one of the best closure plans in the nation. In fact, we recognized him, and our national organization recognized him, and gave him a national and state award for that initiative. And as a result of the closing of those three state institutions, there was major opposition from the American Federation of State and Municipal Employees (AFSCME) union, as well as you might suspect their parent group, and they were in the process of closing down the state institution in Centralia, it's called Murray. That was a very, very aggressive campaign to keep that facility open. They filed lawsuits that I hate. They filed an upside down Olmstead lawsuits. The court did throw that out. They needed a re-election issue and the new governor, (Governor Rauner, who was elected), said that if he was elected he would keep the state institution, in Centralia open. In fact, he donated some money for their cause, he wrote a check for $5,000, yeah, chump change for him, but yeah, Quinn is out and Rauner's in. We're about to see where his priorities are Wednesday when he'll have a state of the state facility meeting to be addressed and we're already seeing some messages that nobody's going to like what ..is put on the table in a couple of weeks.
>
> TP, transcript, 2015.

I followed up with a question to understand the political, social, and economic landscape, of the new leadership.

> NC: Do you have any idea what that (budget) might look like for DD (Developmental Disabilities) right now?
>
> TP: I'm not feeling good.
>
> NC: Since there was a big change over?
>
> TP: In all human services, including disability.
>
> NC: The Department of Mental Health and DD is the governing body for persons with intellectual disabilities that would be involved with Olmstead.
>
> TP: The Division of Developmental Disabilities is part of the Department of Human Services. We have a super human services structure here in Illinois, as do many states.

For clarification of my question, when there is a new political party in office what happens in government is a change in state departments including administration. The Department of Human Services continues to experience turnover in administrators, which creates a barrier and gap when researching for materials associated with litigations. The vast expanse of this state department and numbers of persons it serves presents many possible gaps in service to those in need as demonstrated by the filing of the Ligas lawsuit and three additional Olmstead related lawsuits. The three additional Olmstead related lawsuits are not part of this study because the focus group is much different.

I continued to discuss with TP areas specific to the current Ligas decree, in relation to the Olmstead decisions and what this means for Illinois. TP expressed how the state has made great strides and progress; however, the last Governors election cost them in terms of advocacy and having to start over. TP expressed the agency's priority has now turned to employment. This is an area within the Ligas implementation plan and the Illinois Blueprint Tipping Point.

> Well, we are headed in the right direction these last four years. We've seen tremendous growth in the community. We've seen an emphasis on employment, we've seen an emphasis on the... kind of the, money follows the person model, you know? In terms of new supports and services. Well the continuance of the old system. So you're developing a new system and new ways of doing things but you're still investing in the workshops and the large group homes and things like that.
>
> Now Illinois, with the new governor that was elected, ran….and that's what he is, a businessman, and then he's saying that we have spending problems here in Illinois, we're living beyond our means, you know, the advocates would say we have a revenue problem here in Illinois, so we're…the next two years, I'm thinking will be very painful for disability and human services in general. We're looking at a loss of revenue. We lost just about 4 billion dollars because the state income tax increase was not extended, and the current administration sees no reason to replace that, so when you see 4 billion dollars plus the problems that they have in terms of paying for the state employees' pension and teachers' pension, it's a pretty insurmountable figure where everybody's going to have a lot of pain trying to balance a budget without those resources. Is that clear?
>
> We have to protect low level individuals and he just mentioned people with disabilities, but the dollars and cents don't add up to me. And again, we'll know in a couple of weeks, exactly what that means, but he's been going around the state and what he's been saying around the state is problematic.
>
> TP, transcript, 2015.

**KZ, President and CEO, service provider organization**.

KZ is the President and CEO of a major service provider in the Western Suburbs of Chicago. The agency has been providing community-based services by contracts with the state of Illinois. KZ has been with this agency for over 21 years and in her current role for over four years. I wanted to interview KZ because of the agency's involvement in various areas of state advocacy and a leader in the provision of innovative services for persons with disabilities. KZ and I had some challenges in arranging the telephone interview due to KZ's many roles and responsibilities. We were able to conduct this forty-five minute interview by phone from our offices. KZ was very open and did not appear to hesitate in answering the questions. KZ discussed the agency's background information and the extent of services provided and the Olmstead connection. KZ's interview links with all five of the core concepts.

> The community-based providers are specifically the agency's attempts to respond to the need of people that are in the community and wanting to live in locations that are smaller and not segregated, but integrated in the community. Where that really intersects with an Olmstead Plan is the fact that our service delivery system is less than flexible when it comes to providing a fuller way of options. I guess our role is really advocating that we see some positive change on the front of creating more actions for people, for them to be integrated in a community.
>
> KZ, transcript, 2015.

This agency currently has 22 licensed Community Integrated Living Arrangements (CILA) in the community and a number of people who rent or lease their own apartment with intermittent support from the agency. The state of Illinois recognizes this model as a leader in providing independent living options for persons with intellectual disabilities. This agency has been involved in the implementation of the Ligas Decree from the beginning:

> We still are involved every day. There's two pieces with more and more people in our service area gaining funding, whether it's home-based services or CILA funding, so that they can move into a home outside their family home. The role that we have been playing has really been trying as best as we can to respond to the need and expectations that people have.

> We have had some interesting and very customized success with at least one person who received funding for a one person CILA with some really unique [inaudible]. That's been exciting. By and large, we've seen a big growth in our home-based services facilitation with families that are choosing to keep their family member at home for a variety of different reasons.
>
> We are also expecting, although we haven't experienced it yet, The Council on Quality and Leadership (CQL) who has contracted the state to come in to our Integrated Community Facility/Developmental Disability (ICF/DD) to interview people to determine if they would like to move to a CILA or a different type of more integrated setting. I don't have a time frame on when that's going to happen, but sometime in the future.
>
> KZ, transcript, 2015.

In our interview, it appears KZ shares similar thoughts regarding the role of self-advocates in the process of Ligas decree and their agency's role as follows:

> Overall, this is more a general answer that feeds into what happened with the Consent Decree, is that we support and work with people with disabilities to advocate on their own behalf and do that very much as a part of our mission and our values and how we go about doing our work. I believe that Self-Advocates have played a role in helping to push the system along.
>
> Now, we did not, specifically have anyone from the agency that would've been part of the named class, but we do have people that are advocating for themselves, even though CQL hasn't come here yet or their families, at our ICF/DD saying that they would like to take advantage of the Consent Decree and be able to move to a different setting.
>
> KZ, transcript, 2015.

In our discussion, KZ referenced that the people within the state's self-advocacy movement considered Ligas a huge win. However, the only way to accomplish this was through a class action lawsuit or as KZ states, "how disappointing it is that the only progress made it seems, and is by suing the state and making that happen". My research includes investigation on how an established Olmstead plan might reduce or eliminate the need to sue for non-compliance. The follow up question to KZ was asked more of inquiry and rhetorical than solution finding.

NC: Why doesn't Illinois have a formal Olmstead plan?

> KZ: I couldn't tell you. I don't know why we don't. I think that just like every other state, we should have one. There doesn't seem to really be, at least from my perspective and someone could prove me wrong, any piece that requires that the state respond to Olmstead. I have to wonder if some of the new CMS rules that are now out that states have to comply with are very much in alignment with the value of Olmstead. Is that a way to make Olmstead more of a reality that has a little bit more teeth? I do not know.
>
> I would think that if there was an active Olmstead plan that was moving the system forward and there was at least hope and forward progress, then I think that Illinois could avoid some of the lawsuits.

The class members and self-advocates might consider the Ligas Decree a huge win however this did not come easy. There were other groups in Illinois, who view Ligas as a threat to services, facilities, and other visions they need to protect. KZ provides context,

> I certainly know Ligas started out being a much broader attempt to address the service delivery system than what was ultimately agreed to. That was very clear to me that that was because of private ICF/DD providers that I think felt very threatened. I think it had to do perhaps with some of those ICF/DD providers also being organized by labor unions. I think the nursing home associations that these ICF/DD providers were tied to were barriers.
>
> I think that some of the groups that were opposing this also had the money to give the defense and they fought it tooth and nail. I think it had less to do with a vision for people with disabilities and more to do with protecting their own, I guess.
>
> I can speak for our agency. We've never been threatened by Ligas. We don't intend on being threatened by Ligas. We see it as an opportunity for people. We happen to be a provider [inaudible] that's been around for a number of years, over 60, close to 65 at this point. We have some services that are a little bit more traditional in nature, like an ICF/DD, that maybe we wouldn't build one today, but we have one.
>
> We have seen it as being an opportunity for perhaps some forward progress that we have not been able to make because of the state of the state. I think where people feel threatened is maybe when they also are not a CILA provider, because, they, I believe, do not want people to leave their service system because it's a threat to their business operation.
>
> KZ, transcript, 2015.

I moved the interview forward to the topic of persons with disabilities who might still be living in institutions and/or nursing facilities, either public or private. I wanted to gain an understanding of the progress, in Illinois and the deinstitutionalization movement. I expressed to KZ, I recently heard that approximately 21,000 persons with disabilities are living in either private nursing homes, public institutions or other facilities. KZ expressed she had not heard this statistic, lately.

> My go-to place would be David Braddock's State of the State report to get that data. I think that the census has been slowly decreasing….Or Tony Records would probably have that in his Year 3 report, too. I can't tell you the number, but I do believe the census has been decreasing for a number of reasons. Ligas people are starting to move. When you move, it doesn't mean that that provider can't backfill at that bed, so to speak.
>
> I also think that the primary movement has been that there has been some ICF/DD providers that have converted ICFs/DD to CILAs. A couple of the larger ones in Central Illinois, like St. Mary's Square , was one that I know moved people or they've closed their ICF/DD and built CILAs now. There was a lot of debate about how they went from doing that, but that's a completely different story.
>
> I think the options are more limited and I think they've become mini institutions that are part of the community. I have to wonder though, with the state of our state and our economic situation, not just Illinois but also the whole country, has been facing, does it make it more of a threat? Do people see it as being more risky now that maybe what it would've been viewed 15 years ago? I don't know, I haven't really given that much thought. It does occur to me, particularly when that is your bread and butter, so to speak. If that's your ICF/DD, that's the biggest part of your operation and you don't operate CILAs, you're not in the CILA business and you get concerned about that person moving up the street to provider X is I think what scares people.
>
> KZ, transcript, 2015.

The Ligas Decree indicates over nine years, 3,000 class members will move to other communities. What are the economic aspects associated with the options to move to other facilities of choice, considering in many communities housing options are a concern, including affordability. KZ explains,

> Here in our home [inaudible] area of DuPage County, you know very well yourself that affordable housing is few and far between. It's a huge issue here in DuPage and the greater Chicago metropolitan area; I think in some parts of the state it would have to be a bricks and mortar project. Being able to get the capital has been a little bit more of a challenge.

> For a period of time, and we're still not off the hook, many providers around the state were having to go into their line of credit to make the payroll, because the state was so delayed in payment that providers were openly stating that they just were not willing to take the risk to open another home.
>
> I think if you look at it from that perspective, you can hardly blame people. We're definitely more conservative today than what we were a decade ago, just with what we choose to do moving forward because we need some infusion of resources into the system.
>
> KZ, transcript, 2015.

DuPage County is one of the more affluent counties, in Illinois, which has political ties and economic resources to advocate for services to administrators in the state agencies. This does not mean DuPage is not without their challenges in providing services to those with disabilities. KZ's agency is just one of a few who have been around a long time and understand the economic issues that face people with disabilities, such as funding through the Medicaid waiver and Money follows the person. However, there are specific parameters associated with Money follows the person. KZ provided understanding:

> If someone moves out of an ICF/DD, they would need to move to a setting that is for fewer people. That, too, has been a challenge because Illinois the average CILA is about 6, maybe. Not because providers set out to six person CILAs, but because of being able to keep their doors open, you had to operate them that way. Yes, I believe that we still are under Money follows the person.
>
> KZ, transcript, 2015.

By understanding the economic impact for persons with disabilities and having, an option to live where they choose provided the opportunity to ask about how the class members associated with Ligas would fare in comparison. KZ response,

> Yes, 3,000 people off the Priority Utilizations Needs System (PUNS) list and then anyone in an ICF/DD who wants to move. They are specifically contracted to go to all ICF/DD providers and with permission of legal representative or guardians, interview people and ask them if they would like to move or if they would like to consider a different option. I think the Consent Decree was specific that it had to be neutral, third-party entity that makes the [inaudible] so that there would not be any conflict of interest, which I think has been met with a great deal of res istance in some parts of the state.

> When you put it in perspective, it really doesn't make a dent in the needs. You would think, so, right? You would think so, because Ligas says that after the monitoring, its nine years, then the state needs to move people off the wait list at I believe what they would consider a reasonable pace. I can just imagine that 22 attorneys are going to gather around the table and debate for weeks and months about what a reasonable pace is.
>
> You would think if we had an overarching, active Olmstead Plan that was the guiding force, there would continue to be progress in addressing the conflict. You would think. I don't. I think they were two separate and distinct issues. Frankly, from a coordination standpoint, I wish that maybe they were connected to the greater; we will call it Olmstead Plan perhaps, because you had so many different parts of the system working in silos to accomplish different types of goals.
>
> We were spending a lot of time monitoring and being involved in conversations about the people that lived at Jacksonville Developmental Center and Murray Developmental Center, which we decided at one point that we would most certainly entertain people who would be interested in moving and having our support.
>
> We needed to really focus on taking care of our own backyard, because we have many families coming to us here. It was really a lot of overlap and pressure on a system that's already about ready to break.
>
> KZ, transcript, 2015.

Finally, I was able to get to the heart of my research, reasons and challenges facing deinstitutionalization, Ligas and Olmstead and the impact on persons with disabilities. It appears the providers understand closure of major facilities will and can have economic implications for the persons with disabilities, families, and employees. If closing two facilities in areas where there are no other known resources, where do you move people? It appears families and persons with disabilities begin to county shop for their options, however finding an agency that is not already under pressure or has a lack of resources and space can and will create new challenges to a system in danger of collapse.

KZ provided context to making connections and to the challenges faced with the deinstitutionalization movement of the 1970's, when people were being moved out of closed institutions however there was no support services to follow. The similar challenges were encountered when Jacksonville Development Center and Howell Developmental Center were closed.

> We had to strategically decide where we were going to focus our efforts. Centralia never really got off the ground, let's face it, but Jacksonville, I just kept thinking to myself, well not, not to myself, I vocalized it, pretty loudly, too, not that people living there are any less important than anyone else, but if you truly wanted to make this a success, why wouldn't you look to downsize or close a location in a part of the state where you have resources? There's nothing in Jacksonville.
>
> I would get phone calls a couple times from the governor's office asking, "Would your agency open up shop in the Springfield area?" No, we're not going to do that. I don't know. I'm always skeptical that I'm sure there was probably a political reason that that location was targeted. No, it was people were leaving with high rates [inaudible], which was surprising to hear.
>
> Person-centered Plans were being developed and they were getting rates that we've never seen before. Now on the other hand, you would have someone with the exact same profile and support needs that's already living in one of your homes today perhaps or someone who was being funded through Ligas that has very high needs and there's no way that they're getting those types of rates. (Note: rates refer to the dollar amount charged per person for services).
>
> Some providers I think jumped in on the action of closing Jacksonville that maybe did not have any business doing so, because of funding that was being made available. I think that we may live to regret that at some point. Also, what ended up happening is that after the first year of providing services, those rates dropped significantly. They've been reinstated, but it just fed right into that distrust that [inaudible] have trying to go onto a limb and expand their services.
>
> There was a lot of discussion about what's been happening. Are we creating a two-tier system for people leaving state-operated developmental centers versus people who are already a part of Ligas Decree or already in our CILA system? A two-tiered system, can you have that under Medicaid? Can you have the haves and have-nots? There was actually a lot of discussion about is the state leading itself down the path, yet again, for another type of lawsuit?
>
> KZ, transcript, 2015.

Illinois still has six institutions operating to date and based on information , KZ provided information on the average cost per resident in an ICF/DD is $225,688 as opposed to the average CILA award of $6000.

> NC: With the change in political people and a new governor, what are your thoughts as far as he and his cabinet trying to move to more of an Olmstead Plan forward, as opposed to the continuous revisions of the Blueprint?
>
> KZ: I think what I know is that he met with a couple CEOs and myself, in our area and he was very engaged with what we are doing, how we were doing it, concerned about the financial stability of the system. He seemed to be educated on what was presently happening and voiced his support to community-based services. Then about a month later, within Centralia, saying that he is keeping Murray Developmental Center open. That was part of the political campaign.
>
> I think that this governor is a good businessperson, obviously. I think he surrounds himself with really smart people, that I can't help but think when you show those figures of how much it costs the state to do the same work we're doing, that he's going to look at that really long and hard. Maybe so he doesn't close Murray, but maybe he comes up with another plan to continue to downsize the system and support community-based services. Yet, I don't think he just can ignore that. He already took the fight with AFSCME, the largest union in Illinois.

Funding for services for persons with disabilities and other social services are a continuing challenge given the state of Illinois cannot make pension payments or meet deadlines for other necessary budget items. How will the state make the payments for essential services and continue to honor the requirements of Ligas? It appears new litigation filed in early 2015, is meant to protect the financial allocations per the Ligas plan against any impending budget cuts.

The outcome to this litigation has no known answer and only time will be the experience. I inquired about what the future of an Olmstead Plan looked like and who the champions are:

> Self-advocates are perfect to promote it. I really believe that getting back to some of the grassroots efforts that I think we used to do well a long time ago is important right now. When I walk into a legislator's office or anybody, they know exactly what I am going to say. They know what our priorities are.
>
> They need to hear it from people that get services in the system that we need to do better. It needs to be, I think, Self-advocates that again, not necessarily go and take our

> signs and make a stake down in the field, but a coordinated effort, of "We demand more. We demand better."
>
> KZ, transcript, 2015.

KZ expressed that many special interest groups will all be going after what limited resources are out there and the investment in providing training to the Self-advocates and families is the way to go. If the self-advocates and families want to embrace the current Blueprint then going to the powers to be and telling them to make this the Olmstead Plan and fund it. The challenge will continue to reflect the geography of the state, different values, beliefs, and support services.

**CY, Program Manager, Ligas Outreach Project.**

CY is Product Manager with the provider designated by the Ligas Outreach Project, which is part of the Ligas Decree. This is a private contractor hired to conduct outreach to people living in ICF/DD facilities licensed for nine people and who began receiving services from June 15, 2011. We conducted our interview by phone for thirty-eight minutes. I interviewed CY because of the work this agency is providing in Illinois and the direct connection she has to persons with disabilities living in ICF/DD.

CY acknowledged the state of Illinois' current political, social, and economic issues by expressing views from the lens of an outsider; she does not live in the state of Illinois. CY provided as much information as possible due to the nature of her position and responsibilities to the consent decree. She was interested in providing statistical information regarding the number of class members consulted with or who are now choosing to move into a less segregated facility. CY has completed much of her work in the central and western part of the state, because these are areas identified as having very little in options available.

I inquired about the connections to a state Olmstead plan and what role self-advocates can play in delivery of the requirements,

> Because we have very limited contact, we are focused on the legal decision maker when we do our outreach, although we encourage the guardian to include the person. That does not happen routinely they are included in the decision-making. I actually have some numbers I can share with you if that would be helpful.
>
> We met with the decision maker for 203 people who are potentially class members. Of those, 51 people that we've met with had legal guardians, and eight of those meetings have included the person with a disability or self-advocate in the meeting. We have also met with 152 people who are legally responsible for their own decision-making and therefore would not have a legal guardian but may have other supporters included in the meeting.
>
> CY, transcript, 2015.

The information provided demonstrates an honest attempt at following what the Ligas decree stipulates such as offering choice and options for living independently. The numbers are not large, however it was a beginning, especially given the geographic areas of Western and Central Illinois. These rural communities have very little options and choices available. The process for conducting outreach in these rural communities can be challenging and methods to provide information described as:

> What's helpful in that we have developed some materials, although they're focused on the Ligas outreach, that help to be able to describe the waiver option, hopefully in a little bit more plain and regular, everyday language. Then we developed a video. The video is very focused on Ligas class members and people having knowledge of what happens and what kinds of services are available for the ICF/DD program. We developed written materials that we are able to share not only with the legally responsible decision maker, but we put on our website and told past agencies. We are hoping that will help for a broader understanding of what home and community-based waiver services; or what non-institutional services look like in the state of Illinois.
>
> If you have intimate knowledge of the system, you know that in the past when I asked for the initial service descriptions I was told to look in the waiver. So, I looked into the waiver that was submitted to the federal government to approve, and we don't always use the language in there that is easily understood by people not in the field. It has nothing to do with whether or not somebody has a disability or not. It has to do with whether or not they have exposure or experience to jargon.
>
> CY, transcript, 2015.

I wanted more detail for a clear understanding of the class members and how are they located to begin this process, which adds additional information on the compliance of the Ligas Decree.

> NC: How do you find some of the people that you've been working with?
>
> CY: The state has given us a list of people with whom we are intending to conduct outreach. Then we go through a process of verifying with the provider that they are still receiving that service from the provider. If they're not we try to find out where they are in case we do need to do outreach with them. In essence the state identified the people that we do outreach with.

I examined the annual reports of Tony Records (2012-2015) the court appointed Monitor of the Ligas Decree. It appears the names CY references, are the state's agency responsibility and has had many compliance issues, such as wait list; crisis lists; the system collecting non-essential information; and no current information regarding who receives services, where they currently live or up-to-date death verification. The Monitor reports the data tracking system the department uses is out of date and needs to reflect accurate records. In response, the Monitor's report indicated the need to hire additional state department employees to correct the deficiencies.

> CY: I'm sure the CMS came out with new regulations and guidance around waiver services which the state is supposed to be developing a five year plan with input from stakeholders, and how to implement these very good things that are focused around self-direction and not just presence in the community but community membership and inclusion and all of things. I think the state has been so focused on problems that they really haven't begun to look at what can we do differently to move ahead and be better at this. I've been watching for and listening for the transition plan development and haven't heard much about it.
>
> NC: Is it 20,000 or more persons with DD that still require not only services or the money follows the person but home-based services possibly that might still be in an ICF/DD, or an institution of some kind, nursing home?
>
> CY: There is the whole system. We were told that when we started doing our work that there were about 9,000 people in private ICFs. Then when you start adding in the state ops and nursing home, I'm sure that you're probably absolutely correct on that number. Again, some have become class members, and have elected to and are now receiving services in the community. But one of the concerns from some of the advocates and …. [inaudible] is that the way that [inaudible] are funded and operated make them just another type of ICF, another type of institution that isn't responsive to individual peoples' needs.

Over the next nine-years, the Ligas Decree will provide services to identified class members. However, the implementation of this decree is still meeting with opposition from the major service union and some parent groups. There appears to be a fear factor regarding choice and options available.

> I think people’s fear was that they don’t know and that the state of Illinois has…I could tell you a horror story about somebody who was receiving services in an ICF and that group of people could come up with a horror story about people who are receive waiver services. Really, I think one of the barriers is getting out those success stories and those things about how well people’s lives are going…..I don’t know that there are enough positive stories out there, so people are afraid. We have led people to believe that there is safety in numbers.
>
> CY, transcript, 2015

CY interview links with the themes of Individualized and appropriate services, capacity-based services, integration, and autonomy.

### DC, self-advocate and litigant in Ligas class action suit.

DC is a young man in his early thirties and one of the major litigants in the Ligas v Maram suit. I conducted this interview in DC's family home with his parents, present. DC's parents provided clarification and assistance in DC's ability to understand and answer the questions. DC was interested in providing information from his lived experience of being a person with an intellectual/developmental disability. The interview was seventy-four minutes long. I corresponded with DC's mother via email to request permission to interview, provided the necessary consent forms, and explanation of the process.

DC was open to participating in the interview; however, there appeared to be some hesitation on his parent's part. I can understand this from the personal perspective of being a parent of a person with an intellectual disability; you are not sure what the motive might be or questions asked and the answer your son or daughter may give. There are numerous concerns, which I took into consideration. At the end of our interview, I explained that I was a parent and understood the concerns, challenges, and issues persons with disabilities encounter. I conducted the interview toward DC, however due to DC's difficulty in communication his mother did much of the answering. This appeared to frustrate DC at times because he wanted to answer. When asking my questions, I maintained eye contact with DC so he understood what I was asking. If I sensed DC was having difficulty understanding I re-phrased the question, or one of his parents would comment. I wanted to interview DC because of his involvement and experience with the original Ligas lawsuit and his current living arrangements. DC's voice is the lived experience.

The interview process was uncomfortable in the beginning and sensed the need to jump right into the purpose for being there. For purposes of identification of speaker J1M is the mother and J2F is the father.

NC: Where do you currently live DC?

DC: Group homes, yeah.

J1M: They are opening group homes. They got a grant from somebody, a big grant.

J2F: When was the lawsuit?

J1M: Three years ago

DC: Yeah, three years ago

J1M: DC has been living in his home for two years, March will be three

DC: Yeah

J2F: That took at least a year or two to get a spot.

The interview was posing some challenges in the direction and style of questions and answers. I wanted to have DC answer, however his parents continued to do most of the answering or the interview would take another turn. I decided to change the format.

NC: Tell me how you decided that you wanted to go forward with the lawsuit.

DC: I had to sit there for a long time though.

J1M: I think he meant in court.

I understood what DC was expressing, however I, also, understood from the perspective of being a parent of a Person with an Intellectual/Developmental disability (PWIDD) the need to protect and speak for the person with a disability.

DC: In court, such a long time. Then they say, “[inaudible] no, we don’t have this, we don’t have this and that”, I was like, “Okay [inaudible]”.

J1M: Not the best experience, ask his father.

J2F: We were just part of the process. It really was…E and E (major legal firm) was really responsible for what was going on, so they were young lawyers representing their agents.

J1M: They went to Chicago the first time

DC: Yeah, Chicago, first time in court.

J1: Everybody testified. There were how many people from an opposing private facility, against that and they got….Well E and E thought they were going to win. They thought the judge was going to….The next day he said no. Then they had to negotiate another year or so. Remember that? All the politician really liked her (the spokesperson for the private facility).

The situation J1 is referring to is the upside down lawsuit filed against ADA or otherwise known as a reverse lawsuit. The opposition stance tried to take the Olmstead law out of context and referred to mass closing of facilities and moving people to other places without supports. An opposing group of families, known as the Murrary Parent Association (2013-2015), located in downstate Illinois, was known for their adversarial position filed the opposing litigation. However, the judge ruled against.

NC: Why did you do this?

DC: I just wanted that choice.

NC: You wanted to live on your own?

J2F: Yeah

DC: Right

J1M: There is a lot of people who live in CILA at CB, who are very disabled, but they can live in a group home. They don’t need a big institution.

I returned to these questions regarding moving out of a current placement and DC’s choice in the matter.

NC: DC, did you express to your parents that you wanted to move out of your facility that you were in?

DC: Yeah, definitely.

> J2F: Yeah, we used to live in New York State before we came here. New York State is much more like [inaudible]. We went backwards in terms of the options we had. We brought the New York State mindset here. We were a little disappointed when we found out what was going to happen in New York. It was not even remotely possible in Illinois.
>
> NC: Does New York have an Olmstead Plan?
>
> J2F: They must…. Then again, if DC stayed in New York, he would have gone without any….Gone through all these loops, into a facility. He wouldn't have his own place to be on his own, but he'd be in a group home. In fact, there were a couple of group homes. We lived in a small town, in New York, Western New York, south of Buffalo. Population 10,000. In that [inaudible] area, maybe 25,000. In that little town of 10,000, there were two or three group's homes, and
>
> DC would have gone after he finished education at whatever level. He would have gone into one of those group homes. That was the stepping-stone. When we got here, we came here in 1994, so you were roughly 20-
>
> DC: Twenty-one
>
> J2F: Twenty-one years old. When we came here he had one year of formal schooling left, and then instead of going into one of these group homes, the best we could do is R facility. It was R or stay home.

It seems DC understands the process for the interview and I understand it takes him time to process and formulate his answers. I also understand how parents want to answer for their son due to his ability to communicate. I continued to probe for DC's answers to question with an understanding J1M and J2F would most likely follow up for clarification; and this was okay. I wanted more of DC's story.

> NC: How could you be helping other persons who want to move out?
>
> DC: I know [inaudible] I knew, moved out definitely.
>
> J1M: There was somebody who lived at R. and we think he's trying to move out.
>
> DC: [inaudible] have a house too now, but [inaudible] first.

The following will demonstrate understanding on DC's part and interactions with one of his parents.

J1M: Oh you told SL to go look at……

DC: I didn't tell SL. He told me who you called.

J1M: His mother?

DC: You talked to his mother on the phone [inaudible] good time. You're talking about time or anything you put down, Ma, so….

The interview was going off track again and I sensed frustration regarding some other issues between DC and his parent, so I went back to the court date.

NC: When you were in court, what was that experience like for you, to testify?

J1M: DC didn't testify

DC: Yes, I …. I testified.

J1M: His father did.

NC: You did?

DC: I testified too with him. Yes, I did speak up.

J2F: A lot of sitting. Not much real involvement.

I was not getting very far with information and not sure what to expect; I was only looking for facts, so I changed questions again.

NC: Can you tell me more? What was the actual process like? How did it start?

J1M: It was funny because I have a friend who is in V [inaudible] who sent me the lawsuit because they were against it. When I read it, I called the lawyer, and I said, "Well, this is such a good idea. Thank you for doing this." She said, "Do you think your son could be part of the lawsuit?" They came out and interviewed us. Then we had to go to the office and do depositions and all DC's records.

J2F: testified a little bit in court.

J1M: You did a little speaking.

J2F: Mm-Hmm (affirmative).

DC: Not [under warrant].

J2F: Yeah, they were just trying for class actions. You have to have people who are representative of the class.

NC: How many besides DC and SL?

J2F: I think six or seven.

DC: Six or seven.

J2F: Ligas is the first person of the list of six or seven. We've actually met everybody who was listed there. Some of them never came to any of the court hearings. It wasn't even necessary for them to be there. Having DC and SL there, it gave a face to the class. They were really representative of a group, rather than representing themselves.

DC: Group, right. Correct.

I was beginning to sense either frustration or a "time to leave" from one of DC's parents. This was apparent when I asked DC and his parents to sign the consent form. I apologized for not having done this sooner. J2F appeared very cautious in what DC was going to sign. J1M assured J2F this was a formality in order to interview and required by the university and if he would like a copy, I can provide this. J2F still had questions about what DC was signing and what the purpose was. I made every attempt to assure J2F my interview was confidential and in no way would DC be exposed to harm.

We talked about how living with too many people was not good. DC expressed "Just too many people. Much better." DC wanted to tell me about what he does at home, "Nothing too much. I have a computer now, I'm happy. Now I have music on there, I have now which I didn't have before. My sister gave it to me for my Christmas present, so I love it. There is no problems."

NC: Where do you work?

DC: I am a custodian.

J2F: He works with his group. This group home is run by this local private group called CB. They have a few CILAs, and DC goes to the workshops. DC also works outside the

> workshop at the Renaissance Hotel. Again, if he was on his own, these opportunities wouldn't arise. There is a group of people that could benefit from that kind of structure without being all in the same place. RS has a problem because they didn't have much infrastructure, even this big, so their workshops seldom had work.

We moved the interview forward to the topic to future challenges DC will face. At this time, his parents are his guardians with his sister and brother-in-law as proxy guardians. DC expressed he does not understand guardianship however does understand he may need to move to Ohio to live with his sister. J2F expressed how DC has great family involvement however expressed concern for people who do not have anyone to support them if there are problems or "they really obviously can't have a kid on their own."

I want to find out if DC had thoughts about what the state of Illinois needs to help people more. DC replied, " I'd say more houses, definitely." J1M and J2F continued to probe DC for further detail by asking if he liked his current living situation and the number of people living there.

> DC: We had seven people living in the basement, but no more. Because he was out in the basement. They moved to the…..He moved to the [inaudible] state, that's anywhere he moved to. Fourteen roommates there though.
>
> J1M: He doesn't have fourteen roommates.
>
> DC: Yeah, he has roommates in that house, and that has roommates because you have roommates with walkers. Everyone argues, have more issues than I would have, because he has more complaints and more phone calls. He calls the queue five times in a week [inaudible] and dial him up. Yeah, [inaudible] complaints about his toes about his fingernails, all this, all what the queue will handle. It doesn't make you left from a job because he had those phone calls. There is nothing [inaudible] strict with him, now [inaudible] will be strict with him and he had to pay $10.00 [insurance] for games that he lost and [inaudible]. It was $10.00 in insurance and he has to pay that much money for [inaudible] that he lost. He owe us money for that. That's all I heard last. He still calls my house too. [inaudible] that's our phone, but it takes money to pay for the cell phone and the phone you have in your house. It's enough to pay for my phone bill, to pay too [inaudible] phone bill. Not his phone bill, but it's going to other people's phone. [inaudible] use the phone for emergencies only, but not whole time around be using to dial. [inaudible] do too because I don't have all that money around to do all this too.

DC expressed that he receives Social Security, however only the pay stub not the actual money. DC shared in our short time, concerns and issues such as taking trips, purchasing a suitcase and explaining what he needed to pack, how phones are for emergencies only and trying to explain this to his roommates. DC explained how to take transportation and purchase his ticket noting that all his money is one big account. He expressed right from wrong with “if I need money I could not go into a bank and steal it because, I would go to prison and I don’t want to go, so, it wouldn’t be safety, so I don’t go there”. DC also shared that he is saving his money for the future. DC’s interview appears to connect with all the core concepts and the lived experience of a person with an intellectual disability.

### Summary of Findings.

The history of institutionalization had a significant impact on many persons with disabilities, their families, development of federal and state agencies (who provide services), and a vast number of advocacy and community organizations. The topic of deinstitutionalization, the Olmstead law, and the lack of an effective policy and plan, in Illinois, influenced the research for this study. The lack of an effective policy and plan continue to plague Illinois with respects to providing services to persons with intellectual disabilities, within the realm of individual choice, independent living, employment, and socialization. The state continues to face a number of litigations for non-compliance within the requirements of the Olmstead law and the ADA. The Ligas Decree provides one assurance for 3,000 persons with intellectual disabilities, known as class members, the choice of community living, employment, and the opportunities for social integration.

Information gathered from the interviews demonstrates that the state is moving in the right direction to remedy some of the challenges faced with provision of services to PWIDD.

The Ligas implementation plan provides self-advocates a venue to express their autonomy and exercise choice. The Ligas Implementation plan has made progress in reduction of persons on the wait list and/or for those in crisis. Once the Ligas Implementation plan has ended this may result in additional litigation.

The current state budget is in limbo and the answers cannot be determined. Advocates, service providers, families, and key stakeholders continue to keep a watchful eye on the progress of Ligas requirements and the connection to the state budget. These groups continue to provide information and education to explain, what Ligas is, what it is not, and how this will assist those who are hesitant to experience choice.

The data findings make connections to the research questions and core concept themes, of Individualized and appropriate services; Capacity-based services; Empowerment/Participatory decision-making; Autonomy; and Integration.

Chapter Six will provide an analysis and interpretation of the findings in this chapter and make connections to the research questions.

# Chapter Six

## Discussion

This chapter will provide a discussion and summary of the study drawn from the data in Chapter 5. The analysis section will discuss the historical underpinnings and current themes and make a connection to how the past made an impact on the present. The interpretation section will provide a personal reflection on what I learned, what does this mean, and do I see a connection between the current lived experience of persons with intellectual disabilities, oppression, institutionalization, and the Olmstead decision, in the state of Illinois. The chapter will close with implications for research, limitations and recommendation for further study, and concluding remarks.

### How the past made an impact on the present and where we are today.

#### Community-based service.

The historical connection between oppression, institutionalization, and the Olmstead decision, begins by reflecting on the past history of State Operated Developmental Centers (SODC) to construct an understanding of the current record, in which Illinois has reduced the number of SODC's. The reduction of SODCs and the Ligas Decree provides PWIDD's with options and choice to move out of the centers and into the community.

Illinois has a long history of developing SODC's beginning in the 1800's. These facilities provided a place for persons society deemed worthless and an economic burden. Medical professionals had the responsibility to tell families to place their children in these facilities, because of the burden they would carry for life. Society continued to create the political, economic and social barriers faced by PWIDD and their families. Nationally, SODC's reached its peak population in 1967 with 194,650 persons with intellectual and developmental disabilities residing in these facilities (Braddock & Hemp, 2008). This number of persons residing in institutions resulted in a call and new response for the construction of smaller state facilities.

Parish (2005) conducted a study on advocacy, policy and other social forces connected to PWIDD and found that in Illinois "downsizing of the public institutions was facilitated by accreditation requirements and not through community home development" (p.225). Parrish continues, "in addition to requiring deinstitutionalization, the ICF/MR programs were seized by Illinois as an important primary funding source. The use of ICF/MR program entailed the licensing conversion of existing nursing homes to ICFs/MR,( now termed ICFs/DD)" (p225). In Parish's study , it appears the draw for the nursing home business was more about the current reimbursement rates and DMH's "accreditation policy goals, federal Medicaid funds and conversion to a regional administrative structure to oversee community placement" (Parish, 2005, p.225). Illinois currently has seven SODC's in operation and a new state governor.

**Ligas Decree.**

According to The United States District Court for the Northern District of Illinois, Eastern Division (2009), seven individuals filed a class action suit against the State of Illinois in 2005 "seeking to prevent what they allege is their unnecessary segregation in ICFs/DD by the Defendants (state of Illinois)". The lawsuit seeks

> to compel the State of Illinois' (through the Defendants) to comply with federal law and rulings of the United States Supreme Court, and to bring Illinois in line with prevailing national practices, by offering individuals with developmental disabilities the opportunity to make meaningful, informed choices about whether to live in small, community settings which would provide independence, privacy and integration, in addition to the ICF/DD choice.
>
> Ligas v Maram, No. 05 CV 4331

The Ligas Decree and 2013 Implementation plan designates the moving of 3,000 class members with intellectual disabilities into a community-based setting over the next nine years.

The Ligas Decree and Implementation plan further states the use of optional closure of an SODC or other facility that houses more than 20 persons. The last count for persons residing in a SODC was 21,000 of which 3,000 are class members.

DC's father can describe the lived experience of PWIDD within a SODC,

> With 100 people, they had a wide range from people who were really disabled to people who could clearly live on their own. Since they are all in the same institutions they basically all had the same kind of treatment. The thing that's perplexing, since there is choice, why did they think that everybody is going to opt out of being in an institution? A lot of those folks, it's the best place for them. We are talking about wheelchair bound people that need constant medical attention. They can't go live in the community on their own. There is stages of independence. Some are less independent than others, some are more independent. There are a lot of people who live in CILA's at CB, who are very disabled but they can live in a group home. They don't need a big institution.
>
> J2F, transcript, 2015.

**Legal compliance and implementation plan**.

According to the Court Monitor's first annual report (2012) the state needed to correct their system of collecting data for class members and who would receive services as stipulated in the Ligas Implementation plan. During this period, a group of families from downstate Illinois filed a reverse legal suit by stipulating the Ligas Decree is in direct conflict with the wording of Olmstead and the ADA. The judge ruled against this suit and stated Ligas stands as is. The downstate developmental center was on the state's institution closure list. The family advocacy group was very active in the last election with the current Governor donating $5,000 to keep the SODC open.

The implementation plan as designed with revisions continues to raise concerns for self-advocates and the providers who work with them. CY provides this insight,

> When we started doing our work there were about 9,000 people in Intermediate Care Facilities. Some of those have become class members and have elected to and are now receiving services in the community. But one of the concerns from some of the advocates and some providers is that way they are funded and operated make them just another type of ICF, another type of institution that isn't responsive to individual people's needs.

> When you go from having 16 people living in a home to eight people living in a home, and you have the same rules in terms of people can't go to the corner by themselves or they can't be left home alone, you continue to perpetuate that group mentality of everybody's group and we all go everywhere and do everything together.
>
> CY, transcript, 2015

The Illinois at the Tipping Point: Blueprint for System Redesign (2012) indicates in Benchmark #4, to have an infrastructure, which does not facilitate a measure of outcome or provide a ready process for priority of services for PWID. Tipping Point states

> Illinois articulates a vision and strategic priority to promote person-centered services across the developmental disability service system. This is a critical step forward. Meanwhile, stakeholders express concerns related to three major areas related to quality of life: a) living in one's own home or apartment, b) opportunities for social connections, and c) securing and maintaining integrated employment. (p.v).

The First Annual Ligas Monitor report (2012) indicated non-compliance in some of the same areas with reference to the Department of Health and Human Service PUNS data collection and wait list. The report indicated inaccuracies in the data collected for people designated as class members or on the wait list for services. To reflect a system that conforms to the Compliance Evaluation Standards, the infrastructure needs to be revamped (this is beyond the scope of this study to go into further detail).

### Self-advocates, Stakeholders and Change for Community-based care.

The Ligas Decree and Implementation plan provide PWID's with advocacy tools to empower the participation in decision-making process, which will lead to their autonomy and express the right, not to be segregated based solely on their having a disability. All participants in this study expressed how telling their stories or telling positive successful stories of living independently will reduce the unknown fears many persons with intellectual and developmental disabilities and their families face. The Tipping Point document outlines steps to take; to ensure the system and infrastructure are making an investment in advocacy; strengthen oversight of community services and improve the information system; pursue implementation of managed care system in ways to promote person-centered approaches; invest in home supports; adopt policies for ICF/DD's to transition to HCBS funded alternatives and revitalize CILA; and expand system capacity. TP commented

> Illinois standing in the nation is getting better because of the closure of the state institutions and because of moving people out of the community institutions, but other states are doing that as well, so Illinois may move from let's say 47, 48 to 46, which is a jump, but it's not going higher because of the other states like New Jersey and others are aggressively closing their state institutions as well.
>
> TP, transcript, 2015.

The complexity of the Ligas Decree, Implementation Plan, and the Court Monitor reports all indicate how the "systematic and comprehensive approach by the defendants, coupled with an infusion of significant resources now and over the next nine years" (Records, 2012) will be needed for compliance. The Monitor's first annual report (2012) discussed "Numerous structural, procedural, and cultural changes have taken place over 15 months. In many ways, implementation of compliance related activities has exposed significant flaws in the service delivery system for people with intellectual and developmental disabilities." (p.35).

### Establish an Olmstead policy.

The state of Illinois has three Olmstead lawsuits, that are considered acted upon by the courts. The Ligas Decree has established an Implementation plan, revised in 2013, to address barriers to compliance while taking into consideration the complexities of funding, an outdated data collection system, inaccuracies of class member numbers and a new governor and his cabinet. Illinois has had a Blueprint document, which has recommended policy as underwritten by the Illinois Council on Developmental Disabilities. This Blueprint has been in existence since 2008 with its current revision of 2012. This document could serve as a mechanism to better and more consistent dialogue to establishing an official Olmstead Plan. Or as KZ stated

> That's (the Blueprint) probably the closet thing that we have in the state that is endorsed by the state itself of being….It is funded by the DD council and they continue to update it. I do think that that's probably the go-to document. Maybe it gets them off the hook in some way, shape or form, but I don't know. Why don't they put some funds behind it, put some resources behind it. Whether it's embracing the blueprint and saying, "This is what we want to be official Olmstead Plan, now fund it".
>
> KZ, transcript, 2015.

The political, social, and economic complexities of Illinois are a few barriers but the geography of the state is another. For years, there has been the mentality of upstate versus downstate, or Chicago versus rural communities, or independent providers versus private, or providers with union members versus those without representation. It is possible the Blueprint could serve the purpose as a guide to development of an Olmstead Plan, to avoid future litigation as expressed by CY,

> There is so much waste of money when you have to go to litigation, so that should be the last resort. Unfortunately, most of the time and it's after people have exhausted all of the other negotiations and things that they've done. And it doesn't change the system, and so it doesn't make it different for other people.
>
> CY, transcript, 2015

### Summary.

During the 1960's and 1970's and the advent of new social movements such as the Civil Rights movement, deinstitutionalization, and the Disability Rights movement, provided the platform for empowering families, the public, and professionals to demand closure of massive institutional structures. After the discovery of rampant abuse and neglect were exposed at two east coast institutions, the public outcry for policy change set in motion the deinstitutionalization movement. The Civil Rights Act of 1964 provided the framework for legislation and the passage of the Section 504 of the Rehabilitation Act of 1973; the Education for Handicapped Children Act of 1972 (currently known as Individuals with Disabilities Education Act); the Americans with Disabilities Act, 1990. Self-advocates, families, and providers, who shared a common interest in social justice and treatment for persons with intellectual and developmental disabilities, drafted the policy necessary to send to Congress for passage of these laws.

In 1999, two women, in Georgia, decided they had enough of others telling them where they could live or what they could do. Lois Curtis and Elaine Wilson filed a class action lawsuit against the State of Georgia and Governor Olmstead for the lack of compliance with Article II of the Americans with Disabilities Act (ADA) 1990, referring to the provision of in-community living options. According to the Supreme Court decision, people with intellectual disabilities have a right to receive care in the most integrated setting appropriate; unnecessary institutionalization violates the ADA. All states must comply with the Courts decision by developing a plan that affords persons with disabilities the opportunity to make choices regarding where in their community they want to live, work, and enjoy a quality of life.

Persons with intellectual disabilities, in Illinois, who want to live in the community, continue to experience the lack of a formalized, consistent policy or plan as defined in the Olmstead Law. The State of Illinois continues to move at a much slower rate in the closure of major institutions. As of 2009, the State of Illinois had 13 Olmstead related legal cases and still had no formalized, developed policy or plan for compliance. The State of Illinois continues to develop alternative strategies for policy related to the criteria as set forth in the Olmstead Law. Studying these problem areas will produce an understanding of connections between deinstitutionalization, the Olmstead law, and impact on people with disabilities living in Illinois.

Finally, when the implementation plan is completed many class members will have made the choice where to live. Their transition plans will develop based on their input, needs, and choices. The new Community Management System (CMS) which manages the Money Follows the Person will have increased rates yet not to the level of acceptance. Many PWID will still be receiving money through the Medicaid system, some will have employment, and some will not. This will be the next group of lawsuits to come.

The new governor and adminstration has inherited a shortfall, which led to a stalled approved budget for the next fiscal year. Many interested parties continue to worry about where the money will come from to pay the pensions to state employees, including teachers. It appears, persons with disabilities will be the ones to experience cuts to services due to the existence and continuation of these immense economic problems. This is evident by a new Ligas litigation known as *Agreed Order to Maintain Compliance with the Consent Decree,* filed, June 30, 2015. This order is the result of the continuing budget stall in Springfield. The order maintains that the state continue compliance for all services, programs and personnel as indicated in the current Ligas Implementation plan.

What does all of this mean for persons with intellectual and developmental disabilities? Is there a historical and policy connection? Yes, there is. Illinois' advocates and self-advocates, families, providers, and other interested person continue to work toward an equitable system only to be met time and again with budget cuts, and adverse reaction to any mention or talk of developing a concrete policy associated with the likes of Olmstead and ADA.

The state of Illinois, in all its unique north, south, rural and urban geography will continue to struggle with national practice as discussed in the Olmstead law. It appears Illinois will struggle with the political, economic, and social factors associated with providing choice to PWIDD. The political environment understands a balanced budget and the lack of funding associated with the operation of SODC's. The topic of any future closing of SODC's are met with opposition from advocates who continue to express how the need for services for their family member remains scarce in the community. This is evident in Central, Western, and

Southern counties of Illinois where service provision continues to remain at low standards. The state has Ligas to enforce choice and options for 3,000 class members, however what happens to the other 9,000 plus citizens who want to exercise choice?

NC: In all and all, do you think the legal suit was worth it?

DC: Oh, yeah!

NC: Do you think it's going to help people?

DC, Oh yeah, it will, but it will take time. That's how it goes.

NC: Through time?

DC: It will take time for people to understand.

## Interpretation.

### What I learned.

As I finish the study and reflect on the past as a parent, researcher, and advocate, I know when a parent enters a new culture of disability their language, values, and life change: a life of organization now appears disorganized; the family unit becomes viewed as a medical model not as "normal". Words, images, and negative connotations associated with disability can shape how a family reacts to hearing the news. The mental formation of these words and preconceived notions evoke fear in most families. As humans, we develop our worldview of society by our values and beliefs, and we organize these into concepts and knowledge we gain from understanding our past and current experiences. If a person has experienced negative information, language, and interactions with persons with disabilities, the outcome will be very different from a person who has experienced positive relationships or heard positive language associated with persons with disabilities.

During the 20th century, medical personnel told families of persons with intellectual disabilities to institutionalize their defective child, because they would not develop into a productive individual, capable of learning the skills needed for employment. Families believed the professionals and sent their children to institutions, where there were no choices about how one lived, learned, or worked. The height of immigration prompted professionals to diagnosis additional persons as intellectually disabled based solely on how one spoke, dressed, or seemed different from the norm. Professionals had the authority to say who was deviant of character and keep them away from the dominant social norm. Persons with intellectual disabilities are stigmatized, stereotyped, and institutionalized to keep away from the norm of society and this continues today.

There is not a day that goes by without wondering what life would have been like without my son's disability. This is even more prevalent as he approaches the age of thirty-two and I reach the Medicare stage. This conjures up the dreams and hopes once thought possible however changed and revised to meet his needs. I understand the families who have children in SODC's or nursing homes and unique challenges they experience. I was blessed with providing my son with the comforts of a home, outside medical and social services, an inclusive education and instilling choice and option to his everyday life. I understand some families are not as fortunate. As a parent, I provided basic love and understanding, roots and wings, but I still worry about the future.

I empathize with DC's parents for wanting to speak for him, so he is understood. I can relate to this habitual practice only parents of PWIDD's continue to practice. We want others to understand our children can think, it just takes them time to process the information into what is coherent for them. Adults do not take time to listen to PWIDD's especially if they are slow to process what they want to say. I experience this with my son on a continual basis, from our interaction in the grocery store to family gatherings. When asked a question or comment he is a step behind, in formulating his response, the other party is onto another topic. I witness his frustration in attempts to finish the conversation and gives up. I worry if something horrible happens how he handles the situation. I worry about the future and his ability to remain independent, continue to exercise and voice his choice for options of where to live, how to manage his finances, and attend social gatherings.

As an advocate, I have had the privilege to work with an array of families from diverse cultures, in early intervention through adulthood. I continue to observe the oppression and stigmatization PWIDD's encounter, which enable me to speak out against the injustices experienced. I had the experience with PWIDD in a group home, and they do not always have a say into what they want. The staff tells "clients" when to go to bed, when they will eat, shower, and go on trips. This is not the intent of either Olmstead or Ligas, this is a smaller version of institutional care. It is a challenge to provide information to "clients", who live in private facilities, because staff will tell you, they know what is best. Shades of the past.

Advocacy groups grew from grass root efforts of families who have children with disabilities who recognized the inadequate resources and policy necessary for making change. The strength of the advocacy movement, in Illinois, is strong in providing additional training and skill development to PWIDD on how Ligas can provide options. However, advocacy organizations are careful in their approach to hot topics such as deinstitutionalization and state budgets. We do not live in Illinois anymore, our son wanted to go to college however, we knew and understood this choice was not an option. We found a unique program in Minnesota, which would meet his needs. In this program, he learned to live independently, obtain a job, manage his money, advocate for his needs, and enjoy the company of his friends. My husband and I moved to Minnesota over three years ago because of employment and to be closer to our son for various reasons. I have seen growth in my son in a variety of ways however, I know he will face ongoing societal challenges and barriers.

### What does this study mean?

The decline in persons living in SODC's has become a model based on the Olmstead law and Ligas Decree litigations. I think this is a poignant tale, because it demonstrates PWIDD continue to not have a voice regarding their lives. The only way they are heard is if they file a lawsuit for non-compliance. Illinois will continue being challenged with future litigation until the state comes to terms with another way to do business. Ligas will only cover so many registered class members and families who oppose community options and will continue fighting for their cause. Illinois will continue to struggle with the geographic areas especially those counties with sufficient resources and the counties that struggle for existence. This is inequity in the greater sense.

The state continues to revise a working document based on evidence and research to provide a better way of doing business for PWIDD's and their families. The state could reconvene an Olmstead committee and work together to find solutions to ward off future lawsuits. PWIDD's appear trapped in a continuous bureaucratic nightmare where frustration ends by filing litigation in order to hear their voices. It is time to fund and use the Blueprint as guidance to develop equity and equality in programming and services.

### Conclusions.

#### Implications for action.

Important and relevant institutional and policy-level implications for the understanding of deinstitutionalization, the Olmstead Act, Ligas Decree and Implementation plan were results of this study. The Ligas implementation plan is the beginning and end for some persons with intellectual and developmental disabilities. The Court monitor will continue to report their findings of compliance or non-compliance with the state of Illinois, as required by the Decree. Given the limited economic and financial stability of Illinois and the reality of an equitable and working policy, the state needs to find a solution other than further litigations. Litigations cost the state more than making an investment in PWIDDs.

Future research including reconvening a state Olmstead committee, to include voices of self-advocates, families, and stakeholders to investigate areas where current policy has been non-compliant with the outline Olmstead provides. A larger sample of interviews in which to provide additional voices for understanding the need for a working plan and the intent of Olmstead is to provide the choice of where to live, work, and socialize.

On the policy level, changes in the law may be required in the future after careful investigation, review, and comment of the current Illinois Blueprint Tipping Point and its relation to current federal Home Community Based Services regulations. Research into this area may provide the understanding of the relationship to developing and implementing a consistent Olmstead plan to meet the needs of persons with intellectual and developmental disabilities. The implementation of policy related to an Olmstead plan rather than continuous filing of lawsuits for non-compliance may save the state the financial burden and budget cuts it imposes on the social service community.

### Recommendations for further research.

The following limited recommendations for further research into the topic of deinstitutionalization and the Olmstead Act in the state of Illinois are as follows:

1. Reconvene a state Olmstead committee to review the decision as stated by the courts. The current Blueprint can be a guiding document to provide steps to take in development of an Olmstead plan with the outcome to reduce further litigations associated with non-compliance of federal laws.
2. Conduct a larger research study to include more voices from self-advocates, opposing parties to an Olmstead plan, union affiliates, and other stakeholders to come to an understanding of the state budget and the impact to services due to the lack of a sustainable plan.
3. Further research into current federal regulations and the impact on the economics and/or budget for persons with intellectual and developmental disabilities. Research the financial impact of litigations for non-compliance and the budget savings to prevent future cuts to services.

As quoted in the Illinois at the Tipping Point: Blueprint for Redesign (2012),

> Establish a system that is sustainable, one that is funded and structured to meet the needs of all those in need over time. It must be amply funded, but it also makes efficient use of available public resources to yield high quality outcomes. Establishing a sustainable future for Illinois' developmental disability service system must begin with a commitment to provide quality person-centered supports for all citizens who need them. (p.viii).

### Limitations.

This study has some major limitations, which consist of small sample size for collection of interview data. Four interviews were conducted. Three key-stakeholders were advocates for the system and one self-advocate who was a litigant. Honest attempts in contacting the plaintiff's legal counsel via phone calls and emails were sent, however, no response,or replies received. Attempts were made to contact opposing parent advocacy groups, no response, or replies, so the collection of information came from reading information from the Murray Parent Association online website. I read and reviewed documents from the state agency websites. The insufficient data collected can affect the objectiveness in the analysis of data.

Another limitation to the study is I moved from Illinios to another state, which created challenges with a change in the new state political administration; updated Ligas implementation and monitor reports became available and were difficult to access; and the state economic, social, and political climate continues to change which prevents the inclusion of updated and current information.

### Concluding remarks.

As I fast forward to 2015, I recognize how difficult it is for persons with intellectual and developmental disabilities to voice their wants and needs. For many, such as DC and my son, explaining to people what you want still conjures up looks and questioning of their abilities to choose where and how to live, seek employment, and socialize independently. Families continue to express their concerns about safety, employment, and what happens after we are gone. I question, have we progressed to the point where self-advocates are truly listened to and respected for what they have to say? I am not so sure and begin to question those who hold the keys to change the way services are provided. I find that the Illinois Blueprint can be a document which provides guidelines to developing a quality and workable Olmstead plan.

As CY stated:

> The Olmstead Plan has to focus on making sure that there is good quality oversight and commitment to quality of the services that are being provided in the community. I think to not put that in an Olmstead Plan and not put that in a plan or not have a heavy focus on that almost sets your plan up to not work as well because I think people have to see that the options that are out there are better, that people should expect more than three meals a day and a place to sleep.
>
> CY, transcript, 2015.

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## Appendix A

### List of Table I

**Data source chart: Guideline for analysis of data and research with Core Concept**

| Relevant Items | Disability policy core concepts | Comments/Themes |
|---|---|---|
| Illinois Blueprint-Tipping Point; Ligas Decree Implementation Plan, Transition Plans, Monitor Reports. | 2. Individualized and appropriate services: services specifically tailored to meet the needs in addition, choices of persons with disabilities, and their families. | Choice and options; smaller ICF/DD to 4-6; funding options (Money Follows the person) State budget cuts. |
| Ligas Implementation Plan Revisions; Monitor Reports; Blueprint Tipping Point; Murray Family Association and closure of facilities. | 4. Capacity-based services: reflects a strength perspective and rejects a pathology approach to identification of services to enhance the individual or family capacity, concerns, resources, priorities, and choice. | Transition Planning; class member selection; waiting list eliminations; budget cuts; new litigation (6.30.15) for compliance with Ligas decree |
| Ligas Implementation Plan Department of Human Health Services webpage; Interviews with service providers and advocacy for the state; CQL and litigant interview. | 5. Empowerment/Participatory decision-making: decisions based on individual or family want from a service provider system, participation in planning developing, implementing, and evaluating decisions within the macro/system level and micro/ individual level. | Person-Centered planning; transition planning in western and southern part of state; numbers reduced per Ligas Decree and plan. |
| Ligas Implementation Plan; Court Monitor Reports Interviews | 9. Autonomy: the rights to consent, refuses consent, withdraw consent, or control or exercise choice over what happens to him/her, or if legally incompetent a duly appointed surrogate may do so. To be independent or exercise self-determination. | Reduce wait lists/crisis lists; choice and options for community-based services |
| Interviews; Ligas decree ADA; Olmstead Act. | 11. Integration: the right to not be segregated solely based disability. | Choice, reduce wait lists, closure of facilities; budget concerns. |

# Appendix B

## Interview Questions

National Louis University
IRRB Requirements

The question sets are developed as a guide for an unstructured interview. The unstructured interview will provide an environment of comfort and trust for the individual. The information gathered will be interpreted/coded to examine common themes from other interviewees.

Interview Question Sets for Self-Advocate and family member (if needed). These questions will be used to obtain interviews from stakeholders with different points of view. The outcome will be used in establishing common themes. The following may need to have an adjustment in language for understanding the intent and context for the person with a disability. In no way are the questions meant to decrease one's intellectual ability or embarrass.

1. Tell me about your experience living in an institution, group home, and/or other segregated facility.
2. To what extent did this experience contribute to your understanding of having a choice of where you could live?
3. As a result of this understanding how did you become involved in filing a lawsuit against the state of Illinois?
4. Tell me about this experience of advocating for your rights as designated in ADA and Olmstead Act.
5. Tell me about your family's involvement in this process.
6. After the settlement what did you learn from this experience? How will you use what you have learned?
7. What does the state of Illinois need to do to improve services and establish an Olmstead plan for persons with disabilities?

The following are for key stakeholders, member of legal firm, state official.

1. Tell me what role (responsibility) you have/had in the state of Illinois. To what extent does this role (responsibility) play in development of an Olmstead plan?
2. How do self-advocates contribute to the litigations filed against the state for the lack of a working plan?
3. As a result of litigation against the state and any current settlements, how can these be applied to develop an efficient and much needed plan? What is needed from various stakeholders to implement a plan (I want to follow up with other states and plans)?
4. The state continues to revise the Blueprint for change, how does this impact future policy endeavors?
5. To what extent has the role of the unions and opposition advocacy groups influenced key stakeholders in decision not to have a solid working Olmstead plan in place?
6. What do you see for the future of Olmstead in the state?

## Appendix C

## Informed Consent Signature forms

You are being asked to participate in a research study conducted by Nancy A. Cheeseman, a doctoral student, at National Louis University, Chicago, Illinois. The study is entitled " The Olmstead Act and policy in the state of Illinois: The continuing discussion of the impact on community living options". The purpose of this study is to examine and analyze policy within a historical perspective into the impact of the Olmstead Act and community living opportunities and choice, on persons with intellectual disabilities, in the state of Illinois.

With your consent, you will be interviewed for about one hour in length with a possible second, follow-up interview lasting one hour in length. Upon request, you will receive a copy of your transcribed interview at which time you may clarify the information.

Your participation is voluntary and you may discontinue your participation at any time without penalty.

Your identity will be kept confidential by the researcher and will not be attached to the data. Only the researcher will have access to all transcripts, taped recordings, and field notes from the interview(s). Your participation in this study does not involve any physical or emotional risk to you beyond that of everyday life. While you are likely not to have any direct benefit from being in this research study, your taking part in this study may contribute to our better understanding of community living opportunities and the Olmstead Act, in the state of Illinois. While the results of this study may be published or otherwise reported to scientific bodies, your identity will in no way be revealed.

In the event you have questions or require additional information you may contact the researcher, Nancy A. Cheeseman, 122 South Michigan Avenue, National Louis University, Chicago, IL 60603; (Blocked Cell phone for publication purposes).

If you have any concerns or questions before or during the participation that you feel have not been addressed by the researcher, you may contact Valerie Owen, PhD, student's advisor chair (blocked contact numbers for publication purposes)

______________________________

Participant Name (Print)

_______________________________ Date______________________

Participant Signature

_______________________________

Researcher Name (Print)

_______________________________ Date_____________________

Researcher Signature