

Care and Autonomy

Effects of Liberal Personal Care Policies on People with Physical Disabilities

BY

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THESIS

Submitted as partial fulfillment of the requirements
for the degree of Master of Science in Disability and Human Development
in the Graduate College of the
University of Illinois at Chicago, 2017

Chicago, Illinois

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To Mom, who has always kept me going.

ACKNOWLEDGMENTS

I would like to extend my gratitude to all those in the Department of Disability and Human Development at the University of Illinois at Chicago that have supported me in this process, especially Maitha Abogado, Jamie Cohn-Stacey, and Kristen Salkas. I would also like to thank my thesis committee--Brian Grossman, Sarah Parker Harris, and Carrie Sandahl--for their patience and assistance.

I would be remiss not to thank my family for their devotion to my health and success. Also, I would like to thank Christian Armstrong and Diane Rocke for their diligent assistance and care to detail. I must call attention to all of the assistants and caregivers that have attentively aided me throughout the research and compilation of this project; by their hands I can succeed.

JAG

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LIST OF ABBREVIATIONS

ADA	Americans with Disabilities Act
ADL	Activities of Daily Living
ADRC	Aging and Disability Resource Center
CCDE	Cash and Counseling Demonstration and Evaluation
CEO	Chief Executive Officer
CIL	Centers for Independent Living
CIP	Community Integration Program
CLASS	Community Living Assistance and Supports
CMS	Centers for Medicare & Medicaid Services
COP-W	Community Options Program Waiver
DHS	Department of Health Services
DON	Determination of Need
FEA	Fiscal Employer Agents
HCBS	Home and Community Based Services
HSP	Home Services Program
IADL	Instrumental Activities of Daily Living
ICA	IRIS Consultant Agencies

LIST OF ABBREVIATIONS (continued)

ICF-IDD	Intermediate Care Facility for People with Intellectual or Developmental Disabilities
ICF-MR	Intermediate Care Facilities for the Mentally Retarded
IL	Independent Living
IRIS	Include, Respect, I Self-direct
LTC	Long Term Care
LTSS	Long Term Services and Supports
MCO	Managed Care Organization
MiCASA	Medicaid Community Attendant Services Act
MMLTSS	Medicaid Managed Long Term Services and Supports
NCD	National Council on Disability
PA	Personal Assistant
PAS	Personal Assistance Services
RCAC	Residential Care Apartment Complexes
SCM	Service Cost Maximum
SDPC	Self-Directed Personal Care Agency
WWII	World War Two

SUMMARY

This essay examines the suitability of liberalism to the social needs and desires of the disability community. Relevant literature pertaining to the historical underpinnings and logical make up of liberal theory and policy structures was compared to related aspects in the activist demands of people with disabilities. A cohesiveness of these two worldviews was posited that, if established, argued liberalism possesses the ability to accommodate the political will of these peoples. This suitability was then demonstrated through a liberal analysis of long-term service and support systems in Illinois and Wisconsin.

The resulting paradigm of the independent living movement and its accomplishments was used to represent the goals of the disability community, namely independence through long-term services and supports. The intricacies of classical and modern forms of liberalism were positioned according to the concepts of negative and positive liberty. These two worldviews were shown to share a common view of society and governance, despite theoretical omissions of the disabled, such as that by John Rawls, and both current and historical disparities with the nondisabled. Possible theoretical remedies, in addition to its strengths, such as a balanced approach to governance that makes publicly funded services available while respecting the autonomy valued by disabled peoples. A liberal analysis of services and supports in Illinois and Wisconsin mirrored this intricacy. Shared principles with the independent living paradigm, an ability to provide applicable evaluation of and recommendations for the service systems of Illinois and Wisconsin, signifies that its nuanced view of governance outweigh prior weaknesses, making it suitable to accommodate the needs of people with disabilities.

I. INTRODUCTION

The basic liberty of people with disabilities requires the involvement of the state through various services and supports, however, the dominant theoretical framework for governance in Western democracies has historically overlooked and continues to exempt this population from consideration in matters of equality and fairness despite significant civil rights programs. Given liberalism's intended outcomes of freedom and equality, this is unexpected and harmful. People with disabilities within US society experience undeniable inequalities with their nondisabled peers (Snyder, 2010). Citizens of liberal governments are afforded various rights and corresponding social obligations to one another. These exceedingly liberal characteristics work toward preserving the equal liberty of citizens, yet fall short in that regard when speaking of disability. Despite failings of liberal theory to properly represent the concerns of citizens with disabilities, this philosophy of governance still holds the potential to embrace people with disabilities as citizens and affirm their rights to liberty and autonomy.

People with disabilities desire equal rights to that of their nondisabled cohorts, especially in the areas of the fulfillment of basic needs and opportunities to maintain one's independence. The Independent Living Movement of the late 1960s illustrates the dedication of disabled people to securing access to full citizenship and rights. They argued that human beings have an inherent right to independence, and that society's laws and attitudes toward disability creates significant barriers that often go unnoticed to those that are not inhibited by them (DeJong, 1979; Fleischer & Zames, 2011). Through this movement, disability advocates were able to articulate and assert the often overlooked social obligations required by independence. People with disabilities value

personal autonomy and liberty no less than the rest of Western society, yet liberalism often affords them disparate opportunities for independence (Russell, 2002).

Parity of autonomy, such as that demanded by disabled citizens, is a central characteristic of liberal theory. A view of liberalism through Berlin's (1958) concepts of negative and positive liberty is instructive. Classical liberalism, largely seen through the philosophies of John Locke (1694), views citizens as possessing expansive liberties from intervention and intrusion by the government. As such it advocates strong property rights and protection from the intrusion of others. This liberal viewpoint values *negative liberty* as only formal rights are observed, allowing individuals to pursue their lives, as they interpret them, free from encumbrance by others including the State. Alternatively, modern liberalism, as articulated by John Rawls (1999), puts forth a more progressive view of liberal principles, arguing citizens' rights extend past this basic set of liberties to the social and economic realm; specifically equality of opportunity and the removal of unwelcome inequalities. Modern liberalism values positive liberty as substantive equality is pursued, making it possible for the achievement of opportunities only achievable through cooperation. Citizens are empowered through negative and positive forms of liberty that strive to uphold the value of personal autonomy. This understanding of liberalism demonstrates its value to People with disabilities, given the shared social values and vision to the IL paradigm.

While liberalism holds promise for providing a basis for the protection of equality for people with disabilities, these circumstances have largely not been brought about thus far in the US. The promise of liberal theory for the protection of disability rights is evident in that it and the IL paradigm share a view of human nature that prioritizes personal autonomy. However, any similarities are often inhibited by the observation that it often disregards citizens with disabilities

as members of this protected category. Rawls is a primary example of this form of exemption as he specifically identifies disability as presenting complications for his theoretical understanding of the requirements of liberal institutions to citizens. Despite this lack of theory-based consideration, theorists have demonstrated that logical reinterpretations can command people with disabilities the benefits of liberal citizenship (Hartley, 2009; Sisson, 2015).

As a result, the liberal framework is sufficient to support policies that are inclusive and respectful toward disability issues. Long-Term Services and Supports, particularly in the form of Medicaid waiver funded Personal Assistance Services, play a critical role in enabling the lives of many of the disabled within the US to be lived independently. While all Long-Term Services and Supports focus on promoting the ability of many to live independently, Personal Assistance Services the specific segment of these programs dedicated to supporting the employment of nonprofessional care providers to assist these individuals with necessary tasks of daily living in one's home and community. In so doing, these necessary services and supports facilitate the personal autonomy and self-direction of qualifying participants. The fundamental nature of this liberal goal to citizens with disabilities is signified by their assertion of it as necessary to fulfill their right to an equal sense of liberty of that experienced by nondisabled citizens.

Supports for citizens with disabilities, such as these, must be calibrated to optimize its empowerment for this group. Liberalism's dedication to empowerment of the citizenry through negative and positive forms of liberty suggests these types of programs should be understood according to their ability to empower and promote personal autonomy. The positive liberty, brought about through LTSS, must be offset by a consciousness of the effects bureaucratization and increased taxation have upon economic productivity, property rights and overall autonomy

in the form of negative liberty. Liberal theory is capable of interpreting practical realities of opposing approaches to constructing LTSS systems. Analyzing the Medicaid LTSS systems within Illinois and Wisconsin offers an opportunity to highlight the limited extent of liberal thought already present in the design of these programs and to identify opportunities to build and expand on these. In these states' systems, citizens with disabilities are granted opportunities to have unmet needs for the facilitation of their independence accommodated through state funding of, among other provisions, the aid of nonprofessional care providers. In this way, it can be seen that each system creates a degree of positive liberty to participants of these programs as they become empowered, reaching a degree of independence that is made possible by the collective action represented by such service offerings. Despite this common element, the liberal emphasis on autonomy provides a standard by which each system can be compared and improved. While Illinois may favor negative liberties to an excessive extent, Wisconsin may benefit from embracing these elements to a greater extent in its system. Through theoretical reinterpretations, liberalism is indeed capable of fostering the autonomy required by people with disabilities as outlined in the demands of the independent living movement.

II. AUTONOMY: THE LIBERAL MANIFESTATION OF THE INDEPENDENT LIVING MOVEMENT IN MEDICAID HOME AND COMMUNITY-BASED SERVICES POLICY

Over the past century, people with disabilities in the US have conducted a concerted campaign, working to protect and obtain equal rights granted to all citizens regardless of ability. Leiter (2012) suggests that the disability rights movement thus far can be broken into three waves based upon the parties carrying out its agenda. The first wave, however, was originated by parents of children with mostly intellectually disabilities in the 1930s and 1940s that came to organize around the shared purpose of changing social perceptions and creating a reduction in the stigma and exclusion society had directed toward similar individuals. They wished to create a future in which their children would have opportunities similar to those without disabilities, including the opportunity for schooling, and by the 1960s had assembled into national organizations aimed at producing systemic and political change, ultimately becoming instrumental in the passage of the 1975 Education for All Handicap Act that insured free, appropriate and integrated public education regardless of impairment.

While the independent living movement (IL movement) uses similar methods and motivation to accomplish comparable ambitions, it was carried out by an entirely distinct collection of actors and is thus seen as a single phase of the overall disability rights movement. As the second phase, the IL movement was largely carried out by adults with disabilities (Leiter, 2012). Prior to the IL movement, industrialization had pushed people with disabilities out of community settings where they resided and received care through kinship networks, into institutional-based care settings and deinstitutionalization intended to rectify this occurrence

(Scotch, 2001a). Deinstitutionalization of these patients with disabilities in the late 1950s and early 1960s contributed greatly to this movement by creating access to the community for the future advocates with disabilities that would eventually champion this cause (Fleischer & Zames, 2011). In this way, non-disabled contributors took on much of the advocacy for the interests of people with disabilities up until the IL movement (Scotch, 2001b). This began to change as many new disabled members took up the flag of the IL movement, bringing its issues to prominence on college campuses in the US during the 1960s as war veterans and severely disabled students became a significant portion of the constituency (DeJong, 1979; Fleischer & Zames, 2011).

The disability rights movement transitioned into its third wave when coalitions of advocates from multiple perspectives relating to disability joined together (Leiter, 2012). This phase of the movement had some success in the 1980s when numerous disability organizations partnered with disability professionals allowing personal stories and narratives to be combined with expert analysis to make a compelling case for disability rights. This combination proved successful in 1986 with the reauthorization of The Education for All Handicapped Act (now the Individuals with Disabilities Education Act). The coalition eventually evolved such that parents of children with disabilities, adults with disabilities and professionals versed in disability-related issues united. After two years of stalemate in Congress, this particular coalition in the disability rights movement made what is often seen as one of its greatest strides, the signing of the Americans with Disabilities Act in 1990. The influence of this coalition was evident by the 180 national organizations that sponsored the bill, many of which sending a representative with a disability to speak at the House and Senate hearings. All in all, this phase of the effort to further social inclusion and integration of people with disabilities in the US resulted in the Americans

with Disabilities Act in 1990 and many legal cases (Burch & Sutherland, 2006; Fleischer & Zames, 2011). However, it is the IL movement that originated the philosophy that pertains to the subject of this analysis.

A. **The Independent Living Movement**

Following the blueprint of the 1960s civil rights movement, the IL movement united multiple groups sharing concerns for the plight of a marginalized group working to advocate for civil and benefit rights (DeJong, 1979). The guiding philosophy argued that disability is often viewed in terms of the amelioration or eradication of discomfort, but can also be seen through a lens of social responsibility and addressed in terms of the social barriers that ultimately limit one's access (DeJong, 1979; Rioux & Valentine, 2006). This idea was born out of people with disabilities' desire to live fulfilled lives and professionals' ambition to assist individuals regardless of vocational rehabilitation's views of their employability. In short, the IL movement views the most significant barriers facing people with disabilities as socially constructed rather than biologically ingrained (Braddock & Parish, 2001). Its accomplishments included notable activist efforts such as the protests at the San Francisco offices of the US Department of Health, Education and Welfare. The measures taken were prompted by delays in implementation of regulations necessary to validate Section 504 of the Rehabilitation Act from several consecutive Secretaries. This activism culminated in protests that brought disability issues to some degree of national notoriety, and the eventual promulgation of the necessary Section 504 regulations (Braddock & Parish, 2001). Although, the influence of the IL movement extended beyond its activist efforts. Several founding members, including Ed Roberts, went on to establish centers for independent living (CIL) providing many people with severe disabilities services including

resources, skills training, counseling and advocacy (White, Simpson, Gonda, Ravesloot, and Coble, 2010). The first CIL was opened in Berkeley, California in 1972 and 300 such facilities existed nationwide by 1986. The influence of CILs in the US resulted in a dynamic change in the focus of vocational rehabilitation to servicing clients with severe handicaps and deemphasizing employment related goals (Fleischer & Zames, 2011; Scotch, 2001a). Most importantly, the efforts of the IL movement transformed interpretations of the concept of disability, showing that people with disabilities were capable of being members of society.

Its goal was simple, to secure social inclusion for people with disabilities. The IL movement was an activist campaign by members of the disability community and their advocates that is part of the overall disability rights movement (Eustis, 2000). Among the most notable accomplishments of the disability rights movement is thought to be the 1990 passage of the most far reaching public effort to date aimed at ending discrimination and segregation against people with disabilities the Americans with Disabilities Act (ADA) (Braddock & Parish, 2001). The ADA was established to address social barriers to Americans with impairments in such areas as employment, building access, transportation, goods and services, in accordance with what has come to be called its “twin pillars”: the Civil Rights Act of 1964 and Title V of the 1973 Rehabilitation Act (Leiter, 2012; Ne’eman, 2009; Scotch, 2001a).

Its understanding of inclusion was no more elaborate than the opportunities available to the majority: to use one’s ingenuity to acquire the necessary resources and services to take part in the typical risk and reward one encounters in the pursuit of a personal vision of a good life (Fleischer & Zames, 2011). However, this inclusion calls for intervention at the site of social barriers rather than seeing the only path to improvement as being through alterations made

within the individual themselves (Eustis, 2000; Ne'eman, 2009). The IL movement also promoted the presentation of people with disabilities as consumers and minorities rather than as objects of charity or entitlement. Its viewpoint toward the concept of disability opposed other more widely held understandings of the proper approach to individuals with impairments. The medical model places people disabilities in acquiescent positions in relation to the determinations of health professionals including those from the fields of insurance, home health agencies or medical personnel such as nurses and physicians. Similarly, the informal service model of disability also places people with impairments in a place of de facto compliance to the wishes of their limited care sources including family, friends or other care providers.

The tone of this campaign to advance the social position of and protect people with disabilities has since become more progressive. The early stages of the IL movement championed the resourcefulness and self-reliance of people with disabilities, and focused its efforts toward combatting legislative and social barriers that inhibit opportunities for people with disabilities, including implementation of the aforementioned Title V of the Rehabilitation Act of 1973 (Batavia, 1997; Fleischer & Zames, 2011). Later iterations of the IL movement embraced governmental interventions, arguably to the point of dependency, and became less reliant upon private giving. This position contradicts the view of some in regards to the effectiveness of social interventions by big government. Large scale bureaucracies typical of elaborate social interventions are less equipped to address the individual needs of the disability population. By prescribing large streamlined programs with services that are delivered in a less personal manner, the ability of these policies to provide appropriate opportunities for a diverse group of individuals with numerous impairments is sacrificed (Scotch, 2001a). The later version of the IL

movement sacrificed the personal responsibility it had previously championed for the dependency and paternalism consistent with the strategy taken by the leadership of the movement, positioning themselves and those for which they advocate as an oppressed minority (Batavia, 2001).

Due to the work of the IL movement it was increasingly believed that an inclusive society held the same responsibility for the opportunities available to people with disabilities as it did other minority groups. To many individuals with various disabilities, Long Term Services and Supports represent this responsibility.

B. Long Term Services and Supports and Home and Community-Based Services Waivers

The term describes home or institutional-based services and supports used by individuals meeting certain requirements of program eligibility, typically the inability to perform certain predetermined tasks, for the purposes of increasing the personal independence of the client (also referred to as program member, participant, consumer, patient, etc.) (O'Shaughnessy, 2014). There are approximately 11 million adults over the age of 18 that receive LTSS (Kaye, Harrington, & LaPlante, 2010). In 2012, \$219.9 billion were spent on LTSS (Martin, Hartman, Whittle, & Catlin, 2014).

1. Public and private services and supports

LTSS is addressed primarily through public provision as private insurance suffers from both a lack of utilization and quality. Only 7 million Americans hold a private insurance policy that covers relevant LTSS (Gleckman, 2011; Issar, Mir, Obremsky, Jahangir & Sethi, 2012). This minority position of the private option in the LTSS landscape is not solely a result of

its underutilization or lack of quality but rather the relationship of these two characteristics to one another. Out-of-pocket spending accounts for only approximately 22.4% of total LTSS spending (Martin et al., 2014). Many of these policies are expensive and provide insufficient reimbursements (Mendelsohn, Myhill, & Morris, 2012). A lack of protection against inflation or premium guarantees contribute to these policies' unaffordability (Issar et al., 2012). Insurance providers argue that many LTSS are relevant and desirable to even non-disabled consumers, potentially throwing off the balance of the insurance system with high cumulative costs (Glazier, 2001). So because consumers do not purchase these policies, they become more expensive to cover the cost of the services required by the medically needy, but as they become more expensive, fewer individuals find them to be affordable or beneficial. This relationship has remained the status quo, and as a result, LTSS has become largely a public sector responsibility with Medicaid the primary payer (Fleischer & Zames, 2011). Although publicly funding LTSS through Medicaid increases the availability of such services, it has also caused these services to be inextricably linked to welfare, creating a situation in which people with disabilities must maintain their poverty status to gain access to the service they require for independence (Smith & Feng, 2010). The current policy structure considerably disincentivizes employment for people with disabilities that require Medicaid funded PAS or other services. This deterrent exists as a result of the paradoxical nature of the circumstances of having a disability in the US. When these individuals do obtain employment they are often at risk of surpassing the income restrictions of the programs they likely need to get jobs in the first place or, at the very least, maintain their health and independence. Consequently, most Americans with disabilities holding jobs have only marginal positions or have given up looking for work (Fleischer & Zames, 2011).

More than half of the working-age people with disabilities living in the community are covered by public health insurance including: Medicare, Medicaid or The Department of Veterans Affairs Programs (Livermore, Stapleton & O'Toole, 2011). Medicare however does not play any role in funding LTSS, deferring instead to Medicaid, which paid for 61% of all LTSS spending in 2012 (O'Shaughnessy, 2014). The public expenditure on income maintenance, healthcare, housing and food assistance, education training and employment, and other services for these individuals was \$357 billion (FY 2008). Public spending to benefit people with disabilities is likely to continue to increase as indicated by various factors including the aging of the baby boomers and veterans returning from Iraq and Afghanistan. This level of usage demonstrates that public policy holds considerable influence on the lives of people with disabilities. The likelihood that the number of people with disabilities, and the cost of their care, will continue to rise means that policymakers are under increasing pressure to cut costs. However, rather than simply cutting funding that affects vulnerable populations like people with disabilities, policy makers are likely to focus on balancing their efforts by creating efficiencies (Livermore et al., 2011).

The reliance upon public insurance makes the lack of comprehensive policy addressing the cost for them to live in their homes and have reasonable access to social mobility considerably impactful (Scotch, 2001a). An attempt was made to resolve the social barrier to people with disabilities caused by the lack of affordable or widely available LTSS through the implementation of the Community Living Assistance Services and Supports (CLASS) Act. The CLASS Act was a piece of legislation included as Title VIII of the 2010 Patient Protection and Affordable Care Act. This program was devised with the intention of moving citizens off of

Medicaid through the creation of a national voluntary private insurance program. Policyholders will have the opportunity to contribute funds that could one day be collected upon to purchase long-term care either in a facility or one's own home (Gleckman, 2011). The CLASS Act suffered from many of the same flaws that plague the current private insurance market for LTC including low demand and adverse selection (Kennedy, Gimm, & Glazier, 2016). Without mandated enrollment it was believed that the program would be susceptible to adverse selection, in which not enough individuals with low probabilities of collecting on the policy would enroll to balance more high-risk populations. Another feature that inspired concern was the lack of underwriting or the denial of enrollment or elevated premiums specifically targeted toward populations seen as a high-risk of collecting benefits (Issar et al., 2012). To offset these characteristics it was believed that basic policies were to average \$391 per month (Gleckman, 2011). Surveys indicate that while many working age adults with disabilities are interested in purchasing voluntary government insurance to pay for services related to their care, considerably less are willing to pay more than \$100 per month. Regardless, CLASS opposition centered on its effect on the federal budget rather than salvaging the program through reforms. After the death of a key backer, Sen. Edward Kennedy, and the resulting loss the Senate supermajority by congressional Democrats, efforts to present potential remedies to Congress failed and it was removed from the 2012 Health and Human Services budget (Gleckman, 2011; Issar et al., 2012).

2. **Home and community as opposed to institutional settings**

Many services fall under the umbrella of home and community based services (HCBS), which are LTSS that facilitate participants' continued presence in their home or community and avoid institutional services (O'Shaughnessy, 2014). States can access federal

funds designated for the purposes of HCBS through two avenues including: Medicaid Personal Care Services Optional State Plan Benefit and Medicaid 1915^(c) Home and Community Based Services Waivers (Grossman, 2011; LeBlanc, Tonner & Harrington, 2000). The passage of Section 2167 of the Omnibus Budget Reconciliation Act of 1981 established the Medicaid HCBS Waiver Program. Medicaid waivers allow states to designate funding for specific populations (LeBlanc et al., 2000). Medicaid is a joint program funded through a partnership between states and the federal government offering States meeting federal guidelines matching funds covering the cost of programs (Grossman, 2011). The individual benefits funded with these waivers must be no more expensive than the institutional alternative, allowing participants to avoid institutionalization by providing them services within their homes and the community (LeBlanc et al., 2000). Designed exclusively to benefit individuals eligible for institutional placement HCBS 1915^(c) waivers are the most widely used LTSS funding source by states throughout the country with 1.4 million participants nationwide according to 2010 data (Ng, Harrington, Musumeci & Reaves, 2014).

While home care is a growing portion of total long-term care services (Kelly, Morgan & Jason, 2011), the US policy structure has been particularly biased toward institutional based services, such that states are only mandated to provide long-term care in institutional settings while HCBS remain optional provisions (Fleischer & Zames, 2011). This neglect toward the funding of HCBS necessitated a mechanism to mandate or even incentivize the creation of these programs with the 1999 Supreme Court's Olmstead decision (Smith & Feng, 2010). Specifically, this ruling stated that providing institutional services when an individual can be served more appropriately in the community is a violation of the ADA, and thus, states have a legal obligation

to provide each individual with the option of receiving services in the most integrated setting appropriate for the needs of the individual (Fleischer & Zames, 2011; Rosenfeld & Russell, 2012). This judicial ruling provided significant legal support for the growing demand for home and community based services. While states were only required to demonstrate a comprehensive and effective plan for placing individuals in less restrictive settings and also create a waiting list for HCBS that moved at a reasonable pace, the Olmstead ruling provided public validation to this type of service delivery. Deinstitutionalization was a significant motivation behind the IL movement, allowing many previously institutionalized people with disabilities to receive services in their homes, despite the fact that they often then faced significant barriers to accessing the community (White et al., 2010).

3. **Personal assistance**

One of the most significant types of services and supports is Personal Assistance Services (PAS) (also referred to as home care or home support). These services entail the provision of publicly funded non-medical support for people with disabilities to complete activities of daily living thereby enabling their equal economic and political inclusion into the community and access to society (Krogh & Johnson, 2006). It is believed that the first formal PAS program was developed for polio survivors at Rancho Los Amigos Hospital in Los Angeles, CA in 1953. The program grew out of the hypothesis that this hospital could serve its group of 152 polio patients at a significantly reduced cost through this new concept of home care. Eventually, the program developed such that patients were permitted to train their own personal assistants (also known as care providers), reducing program costs even more drastically (Glazier, 2001). This program signified an initial step toward access to key social opportunities available

today for people with severe physical disabilities. Medicaid has since become the primary payer for PAS accounting for 57% of the total expenditures for this needed service (Mendelsohn et al., 2012).

There are three models of PAS delivery. The first is concerned with unpaid PAS and is referred to as the informal support model, while the final two have to do with PAS performed by paid employees and are defined by their care provider management structure as the agency directed model and consumer directed model (Dowler et al., 2011). The philosophy promoted by the IL movement in the 60s and 70s supports the importance of the independence of people with disabilities. A central component of this belief is in right to self-direction, which is largely inconsistent with an informal care model (National Council on Disability [NCD], 2013). The IL movement identifies a great distinction between the two models of PAS performed by paid care providers, holding that for people with disabilities to be fully independent, they ought to receive PAS delivered according to a self-directed (also known as consumer directed) care model (Eustis, 2000). The self-directed care model delegates managerial-like responsibilities to program participants including recruiting, hiring, training, supervising and replacing providers. The intention of these additional responsibilities is to allow the participant/consumer the opportunity to interpret and address his or her needs (Benjamin, Matthias & Franke, 2000; NCD, 2013). Alternatively, the homecare agency model employs nurses, social workers and paraprofessional aids to care for participants under the supervision and training of members of the agency. Self-directed care is a valued form of service delivery for people with physical disabilities and also holds relevance for those with intellectual disabilities as it allows them the option to have their care delivery to be customized and developed to meet their unique needs by

an individual of their choosing (Eustis, 2000). The need for self-direction has not proven, however, to be a priority for many within the elderly population (Eustis, 2000). Interests among people with disabilities in their 20s for a cash option has also been shown to be lacking likely due to inexperience with and apprehension toward payroll and managerial responsibilities. Conversely, characteristics associated with interest in a cash option in PAS include severe over mild or moderate disabilities, prior experience with managerial tasks, currently receiving informal care and ages between 30 and 60 (Mahoney, Simon-Rusinowitz, Loughlin, Desmond & Squillace, 2004).

Current programs demonstrate the opportunities that allowing people with disabilities to live in the community pose for consumers and the states that provide them. The benefits of PAS include increased efficiency and effectiveness of service delivery, in addition to greater choice, control and empowerment as a result of enhanced self-direction from the understanding of the participant as a consumer autonomously directing the service provider and one's choice of services and how they are provided (Fleischer & Zames, 2011; Prideaux et al., 2009). In 1996, four states were chosen to participate in a section 1115 research and demonstration waiver (Mahoney et al., 2000). The Cash and Counseling Demonstration and Evaluation (CCDE) tested the effects of offering elders and younger people with disabilities the option of receiving a cash allowance for the purposes of remaining in the community in place of services they could have received from agencies (Mahoney, Simon-Rusinowitz, Simone, & Zgoda, 2006). The result of the CCDE showed that the increased autonomy of participants within cash and counseling programs produced improved personal care and well-being outcomes overall, with the same or

lower incidents of health problems, fewer unmet needs and higher satisfaction and quality of life than agency care (Carlson, Foster, Dale, & Brown, 2007).

In addition to effective service delivery, Medicaid HCBS programs administer through sections 1915^(C) and 1915^(I) have a renewed focus on providing person centered plan to participants. These programs are now instructed to incorporate plans specific to the personal goals and preferences identified through the participant guided process and that these individuals should be assisted to achieve these outcomes (Medicaid Program, 2014). Programs available to people with disabilities vary widely in terms of their levels of choice and control made available to their participants. Generally, consumers are afforded opportunities to exercise choice and control in three areas: planning, budgeting and employing. Participants are least likely to access choice and control through budgeting opportunities, as often these opportunities are standardized and delegated to outside organizations, yet they are most likely to exercise choice and control through planning and employing as they are highly involved in employee management task and the development of their care plans (Gross, Blue-Banning, Turnbull & Francis, 2015). Similarly, participants of programs with cash payouts express some concern with pay role tasks, often electing to delegate this responsibility (Mahoney et al., 2004).

In this chapter, I reviewed the history of the Independent Living Movement and its efforts to bring about its vision of society, and demonstrating the obligations society has to ensuring independence and freedom. The IL movement views community-based services (i.e., LTSS) as the policy formulation of this duty. The theory of liberalism purports this same understanding of human autonomy and the need for its protection. To advance this argument the next chapter will provide an introduction to liberal political theory, addressing the key thinkers and core concepts

ideas therein. This introduction will demonstrate that liberalism reflects the initial intent of the IL Movement and has the tools to usher in greater inclusiveness for disabled people to experience equitable levels of freedom to that of non-disabled citizens.

III. A BRIEF HISTORY OF LIBERAL THOUGHT

For the purposes of this inquiry, liberalism will refer to specific philosophical, economic, and political positions, predominantly those in the US and British traditions. The long and complex history of these perspectives, and the multiple usages of the term “liberal” (as both an adjective and noun) have made reference to liberalism a rather intricate task and a course of much academic investigation (Bell, 2014). Regardless, one of the more central features characterizing liberal theory is the fluctuating balance between an individual, yet solitary, liberty and its communal, yet restricting, efforts toward social equality and the definitional distinction between classical and modern forms that it informs. While each form differs on the role of government, both classical and modern liberalism share beliefs in a pluralist society, the justification of a minimal state, constraints to limit arbitrary power, and the desire to maintain a balance between public and private power (Arnold, 2009; Starr, 2007). This chapter aims to provide a detailed description of liberalism, primarily through an examination of the relationship between the concepts of liberty and equality, including a brief summary of the multiple senses of liberty and a review of each of the two distinct forms of liberal thought: classical and modern liberalism. The examination of each form will consist of a base understanding of an emblematic text specific to that form of liberal thought, followed by an exploration of its history and key political features.

A. Two Senses of Liberty

It is instructive to explore the concept of *liberty* given the centrality of this concept to this political and philosophical tradition. Berlin (1958) argues that there are two forms of liberty: the negative and the positive. Negative liberty describes the quality experienced by a person or

group in the absence of state interference (Berlin, 1958, p. 3). When negative liberty is extended, one faces no significant barriers to doing or being as he or she pleases and, in so doing, the abilities of this party or group are the only limiting factor. For example, the 21st Amendment ending the prohibition of alcohol extended negative liberty to the citizens of the US making it possible to purchase alcohol and effectively restoring them with the full responsibility of monitoring and controlling their own alcohol consumption. Positive liberty is created as a direct result of state intervention into the undisturbed occurrence of events solely according to individuals' personal choices and abilities. While the absence of intervention may provide for the potential for individual freedom, it does not guarantee that one will be able to access the fruits of this liberty to the level that one could as a member of a group or a community. However, restrictions on certain liberties enables individuals to work collectively, and according to Berlin (1958), results in a higher form of freedom.

Laws criminalizing the use of a motor vehicle under certain levels of intoxication limit the individual freedom of citizens but are also an example of the distinction Berlin makes through his concept of positive liberty. Despite reducing the freedom of some, these laws are seen as worthwhile as they produce greater freedom in the end. By criminalizing drunk driving, thereby interfering into the freedom of citizens that consume alcohol to operate a vehicle, it is believed that despite this limitation the aggregate freedom is advanced as all individuals are able to safely utilize roadways. Therefore, in applying Berlin's concept of positive liberty to this example, it can be argued that through their mutual citizenship and on account of their reason and calculation of the long term consequences of allowing the consumption of alcohol in conjunction with driving a vehicle, the citizens of the US chose the higher form of freedom.

through state imposed restrictions on their ability to consume alcohol (Berlin, 1958). Through the contemplation of society in terms of citizens' right to freedom, Berlin demonstrates the cause for his categorization as a member of the liberal tradition. His concepts of liberty also articulate quite effectively what is a significant break in the liberal can; the distinction between classical and modern liberalism.

B. Classical Liberalism – Definition, History, and Key Concepts

1. Locke

A foundational figure in the dominant liberal narrative since the dawn of the twenty first century, John Locke has propelled much of this discussion of liberal government from its followers and its opposition alike (Bell, 2014). In Locke's (1694) *Two Treatises of Government*, he argues that in *the state of nature* (a hypothetical scenario that existed ontologically prior to the development of government) there was absolute individual freedom. In this scenario, all individuals were free to do and be as they chose in accordance with "natural law," which affords all of the rights endowed to each individual by God.

Individuals are free to engage in contracts to trade these rights and their corresponding duties. In the state of nature, natural law provides for a fragile sense of peace for those who follow it but many do not, and as a result, the weak are inevitably suppressed by the strong. To guard against these outcomes, individuals in this state of nature sacrifice their natural rights in order to alleviate the condition of man's partiality to themselves, thereby entering into civil society and stepping out of the state of nature through their agreement to place independent and impartial arbiters as judges over their dealings to commonly prevent men from engaging in selfish, partial or vengeful behavior, which leads to conflict and war (Simmons, 1989). As a

result, we see that a limited government is born out of the recognition the need for, and the agreement to, legitimize an independent party to protect man from the selfishness of others, a condition that is ultimately chosen over the freedom of the state of nature.

Locke's understanding of natural law states that all of nature (e.g., land, animals, other natural resources, etc.) is available for the support and comfort of all mankind in common (Locke, 1694). He argues that reason tells us resources must be divided, thus ownership must be determined. Locke's theory of property asserts that each person owns their individual mind and body in accordance with natural law, and the property that results from the mixing of the labor produced by one's body and mind is consequently also owned by that individual (Locke, 1694). Therefore, Locke's civil government restrains the violence of its citizens, and in so doing, creates a condition where one's prospects for success is not dependent solely upon physical ability and coercion or partiality (Ball, 2000). Hence, civil government is the remedy for the inconveniences of the state of nature, but also alleviates effects of physical inequalities.

2. **Classical liberalism explored**

Classical liberalism came together in the 17th and 18th centuries, though its influence on government began with England's Glorious Revolution in 1688 and culminated with the American and French revolutions (Starr, 2007). While not exclusive to liberalism, constitutionalism is a feature of government used to produce liberal characteristics such as the enhanced separation of powers exhibited in the US constitution. One of the most significant features of liberalism is its universal guarantees to citizens, or the notion of *rights*; these commonly include those of life, liberty, and property (Manent, 2010). Largely accomplished through constitutions, rights afforded under classical liberalism are minimal compared to its

modern variant, and are thus accompanied by limited corresponding duties, namely the responsibility for one's own actions and wellbeing. However, those who subscribe to classical liberal positions, do so in large part because of its limited nature.

Classical liberalism is mindful of threats of excess power, such as tyranny and monopoly, but addresses them without the need for restriction of individual freedoms, which are seen as necessary for a productive society. The classical liberal remedy in these cases is to pit powers against one another (Starr, 2007). Separation of powers and checks and balances are put into place to combat devolution into tyranny, while other features are utilized to prevent excess power including a public-private distinction, economic competition, societal pluralism, and contested political elections. In this way, classical liberalism emphasizes economic competition as a form of power deterrent.

Property rights are especially significant to classical liberalism and commonly associated with the 19th century adoption of the economic doctrine of laissez-faire, which is the belief in an entirely free market, or trade devoid of governmental regulation (Block & Barnett, 2005). In the classical form, economic competition is seen as the primary method of private sector power control. Classical liberals are leery of private sector interventions and find competition to be the most efficient and effective manner of protecting against monopolization. Non-intervention of marketing activities permeates classical liberalism with early liberals also using the free market as a governing strategy. While other forms of government championed personal qualities such as glory or honor that often had violent consequences, from a classical liberal perspective, the self-interested citizens with attributes such as frugality, perseverance, and personal responsibility, were intended to produce a peaceful and productive society (Starr, 2007). Adoption of laissez-

faire policies in the 19th century, was further solidification of this motivation. However by the 1880s, laissez-faire and its influence upon public policy had fallen out of the mainstream. In fact, there is some debate over how devoted even the most ardent advocates were to the principles of laissez-faire, as in 1940 the US invested in canals and railroad companies and maintained high tariffs, yet it was significantly less involved in the economy during this time compared to periods immediately preceding and following (Waller, 2006). Laissez-faire practices intended to create large amounts of wealth and prosperity, oftentimes making good on this promise. However, it also has a record of such undesirable consequences as child labor, destitution and wide wealth gaps, environmental destruction, and sporadic economic panics and depressions.

Classical liberalism affords citizens, not only freedom to control their own property, but freedom to practice one's chosen religion and pursue their own conception of the good life (Starr, 2007). These citizens possess political liberties allowing them to select members of public office, as well as civil liberties, the freedom to carry out one's life without interference. Furthermore, classical liberals conceive of a civil society free from governmental control that includes civil associations and the press. This civil society allows citizens to contribute to the unification of society, and to freely speak and act out against the State, creating additional checks on the potential power of the state and ensuring the rights of individuals. In terms of classical liberalism's public considerations, transparency is to be preserved in relatively all State actions with the goals and processes of politicians related to those actions made available to all (Fenster, 2006). Laws are published and made available to all in order to prevent arbitrary interference into the lives of citizens. This entails public trials to ensure realization of the law and actualization of justice.

Classical liberalism's interpretation of liberty largely reflects the concept of negative liberty. Critics argued that overemphasizing negative liberty results in erroneous views of the individual as lacking dependence on social structures (Hay, 2012). Yet, where others see division and separation, liberals see the protection of common values. For instance, liberalism does not condone a unified religion or way of life for any of its constituents, but in so doing, society is unified behind the freedom of conscience. This extends to its view of conflict. Where other states may attempt to inhibit social conflict, liberalism views these as the source of productive debate made possible through the common value of the worth of all individuals and the restrictions placed upon violence (Starr, 2007). Therefore, classical liberalism promotes its conception of community, not through the restriction of freedoms or forced participation in common enterprises, but through the preservation of shared principles.

C. **Modern Liberalism – Definition, History, Key Characteristics**

1. **Rawls**

In *A Theory of Justice*, Rawls's objective is to articulate a method by which society can allocate its resources and the rights of its citizens in a manner that maintains a sense of *justice*. Justice is seen in terms of fairness with regard to *primary goods*, or the most basic resources or possessions in that from these all others can be obtained. Rawls identifies primary goods as: rights, liberties and opportunities, income and wealth, and self-respect (Rawls, 1999).

Rawls's concept of social justice is not meant to discern the proper course of conduct within the everyday life of man, but rather the proper construction of society's institutions, (Rawls, 1999). This focus on institutions means that Rawls's theory is not concerned with the distribution of specific goods to particular individuals. A sense of fairness must be created for all

representative men within society for it to be just. Rawls differentiates amongst representative men using the concept of starting places, which are characteristics relevant to their position in the social hierarchy that are not attributable to personal choices (Rawls, 1999, p. 82). Therefore, representative men can be seen as groups of generalized theoretical citizens characterized by starting places within society and their "different expectations" for the distribution of primary goods, identified for the purposes of their use in the evaluation of society. These representative individuals have reasonable expectations and prospects for the acquisition of primary goods, given their social station. These expectations are generally depending upon the distribution of rights and duties by institutions.

Classical and modern liberals commonly agree there is a minimum level of individual freedom to which all humans should have access to by *right*, and that this liberty ought not to be boundless (Starr, 2007). Similarly, the first principle asserts that all citizens ought to be afforded the greatest possible level of freedom. Thus, he establishes the foundation of equal freedom, much like that intended by classical liberals, from which a set of constitutionally protected basic rights and fundamental liberties are supported. Specifically, Rawls identifies the following set of rights and liberties: political liberty (the right to vote and to hold public office) and freedom of speech and assembly; liberty of conscience and freedom of thought; freedom of the person, which includes freedom from psychological oppression and physical assault and dismemberment (integrity of the person); and the right to hold personal property and freedom from arbitrary arrest and seizure as defined by the concept of the rule of law (Rawls, 1999). This principle only limits individual liberties insofar as they are required to be consistent for all (i.e., one's rights may not impinge upon the rights of another). Further qualifications are placed upon these

liberties through the second principle, which determines that inequalities of a social or economic nature are only to be allowed to remain if they are “reasonably expected to be to everyone's advantage and attached to positions and offices open to all” (Rawls, 1999, p. 53). The first principle is lexically prior to (i.e., takes priority over) the second principle, meaning that the basic rights and liberties of citizens are not to be impinged upon in any fashion (i.e., one's freedom of speech cannot be revoked because it is to everyone's advantage).

Justice as Fairness is grounded in two fundamental principles that purport to result in a just arrangement of democratic equality. Specifically, according to Rawls's, for a state or institution to be deemed just, it must first grant each member equal liberties, and second, any inequalities allowed to remain in society must be consented to by all (i.e., all inequalities must be redressed unless theoretically deemed possible that the least advantaged representative man would reasonably see it as in his interest) (Rawls, 1999). Modern liberalism proceeds from its common premise of a belief in liberty, showing that its protection is not all to which liberal governments have responsibility to their citizens (Starr, 2007). The second principle addresses the inevitable inequalities that would arise from a system of liberties as described in the first principle, if it were left largely unrestricted. The second principle attempts to uphold fairness within social institutions stating inequalities must be to “everyone's advantage” with “positions and offices open to all.” The latter qualification intends to add equality of opportunity to the formal equality of the system of natural liberty. Rawls understands justice as rejecting a system of natural liberty as an ethical basis for social institutions, in that he believes society to have some obligation to ensure a degree of equality of opportunity. A system of natural liberty embraces one's ability to influence their starting position in society through their natural talents

and abilities only. Where formal equality makes minimal attempts at maintaining social equality, providing only that citizens have the same legal access to “advantaged positions,” the addition of equality of opportunity ensures that citizens with an equal willingness as well as talents and abilities have the same chance of success. This fair chance of success mitigates contingencies including one’s starting position, social conditions of fortune and chance.

However, citizens are still susceptible to the natural lottery. As a result, the former mitigates natural contingencies by denoting that inequalities must be to everyone’s advantage, Rawls insists that society must be formulated to be to the equal advantage of *both* the most and least well-off representative men. Rather than allowing any group to subjugate another, or for a rigid sense of equality to be mandated regardless to the harm it may reasonably cause, the difference principle provides particular focus upon the disadvantaged. In more detail, the difference principle states that any inequality is only acceptable insofar as it benefits the representative man who is worse off (Rawls, 1999). Thus, by allowing for inequalities between representative men and ensuring the preservation of social justice, the theory attempts to establish a particular equilibrium between groups, recognizing the liberty and equality of all members of society. For example, an inequality (e.g., wage disparity) would be just if the status of the advantaged (e.g., corporate CEOs) created such economic or personal gain for the disadvantaged (e.g., economic opportunity for the unskilled and unemployed) that it can be seen as beneficial (e.g. attracting more skilled executive applicants).

2. **Modern liberalism explored**

Modern liberalism is the offspring of the more egalitarian aspects of the classical form, arguably becoming the basis for contemporary liberal politics (Starr, 2007). Liberalism, a

theory meant to promulgate equality, was allowing for an exclusionary system in which only *men with property* were seen as possessing the requisite freedom and rationality to be capable of exercising their natural right to full and equal citizenship status, until the 19th and 20th centuries when incorporation of democracy and the expansion of rights marked the beginning of modern liberalism (Starr, 2007). Modern liberalism is seen as an extension of, or built on top of, the above-described classical variation of liberal thought, distinguished by the view that the State should take an activist role in addressing a significant range of societal issues (Arnold, 2009). The modern understanding of an equal right to freedom includes a widening of the definition of freedom to include a greater reliance upon positive liberty (e.g., redistributive policies) and a renewed commitment to equality, including the rights to basic requirements of human development and security. These extended rights and liberties guarantee equal access to personal dignity and opportunity and come with additional corresponding duties. These include the public obligation to fund social programs that contribute to the public's right to certain standards of well-being. Some obligations of citizenship are not mandated, but simply *expected* of a fully participatory citizen, such as responsibilities associated with being a member of an informed electorate. However, the right to public education has come about hand in hand as a universal right seemingly aimed at satisfying this civil responsibility.

Modern liberal ambitions can be described through a shift that took place in the liberal enterprise between 1900 and World War One with the creation of two distinct political movements: new liberalism in Britain and Progressivism in the US. New liberalism was started by intellectuals and political leaders intent on addressing issues of poverty, economic insecurity, inequality, and urban destitution through social programs benefiting the common good,

essentially, breaking down social hierarchies. However, these measures were not to be accomplished strictly at the expense of economic productivity, which differed from socialist projects as the common good being promoted was not advancing a strict equality typical of socialism that would remove any degree of a free market. At the same time, one incentive of these liberal social programs was to compete with rivaling socialist parties in the area via the growing popularity of democracy (Starr, 2007). This modern liberal policy agenda utilizing social programs has become synonymous with the New Deal, a set of legislation later passed in the US in the 1930s creating a vast system of social protections for Americans (Bell, 2015).

On the other hand, Progressives employed a method appealing primarily to middle class America and aimed to improve the function of US institutions through an emphasis on science and the destruction of market corruption (Starr, 2007). Tactics ranged from breaking up large corporations to simply restricting predatory behavior, preventing corporations from building and leveraging power against the public interest, and engaging in monopolizing activity, all without having to elicit complete market control. This was most commonly accomplished through: rate regulation and antitrust laws. The height of the movement spanned from 1900 to 1918, termed the progressive era, but state intervention into the freedom of contract began with rate regulation in the 1870s, and continued into post World War II (Arnold, 2009). In the 60s and 70s regulation extended to Non-economic areas in the US. Concerned first and foremost with the creation of moral outcomes it confronted issues of discrimination, pollution, health, and safety, among others. As of late, modern liberals have become more open to economic views typically associated with classical liberals evidenced by policies such as international free trade efforts being backed by modern liberals (Arnold, 2009).

These fields of thought continued to advance and grow support throughout the 20th century until the 1970s when a wave of deregulation began, which occurred following a period of rate regulation in the US being instituted regardless of monopolization practices, and in Western Europe, as a form of backlash against socialism (Arnold, 2009). This backlash against larger government conformed to a particular school of policy making termed neoliberalism. Inspired by classical liberalism, neoliberalism saw the role of government as being to ensure the efficiency of institutions and activities through privatization or the incorporation of market forces (Davies, 2014). The transformation to a neoliberal form of policy making coincided with an atmosphere of slowed economic growth following the post-war boom and a changing public perception of welfare recipients, but ultimately it was due to the reluctance of the electorate to pay higher taxes (MacGregor, 1999).

Modern liberalism differs from the classical form in several key ways. Depending on one's ideological standpoint, distinctions between these two forms can be viewed as either strengths or weaknesses (Cochran & Malone, 1999). Many modern liberals view assets to a liberal scheme of government in the following ways. First, governmental accountability, particularly for the economy (Starr, 2007). Citizens are empowered to hold officials accountable for occurrences that were previously seen as on par with acts of God or natural disasters such as, high unemployment, recessions, and depressions. This enhanced accountability leads to greater attention paid to measures of substantive equality and consequently, the creation of larger government. The attentiveness to substantive equality illustrates a significant split between classical and modern liberalism (Arnold, 2009). The second is the enhancement of the concept of positive liberty, which benefits citizens through modern liberal policies in two ways. While, this

egalitarian form of liberalism maintains the dual commitment to liberty and equality (Rooksby, 2012), incorporation of elements of pragmatism within modern liberalism has offset the strict adherence to the promotion of principles, namely liberty. The prior emphasis on upholding principles alone, particularly in reference to the protection of personal liberties above all else, had often devolved into individualistic tendencies and the attention to rights without the acknowledgment of duties. Modern liberals argue that the consequentialist practices typical of the welfare state necessitate wider interpretations of personal property allowing for redistributive efforts (e.g., social safety nets funded through more aggressive taxation) (Hay, 2012). These interventions were being argued on liberal grounds, such as the promotion of liberty and a sense of individual value. Social programs characteristic of Roosevelt's New Deal and Johnson's Great Society agendas intended to create universal protections against devastating circumstances of misfortune such as economic downturns, and matters related to aging and health complications (Bell, 2015). Additionally, positive liberty is also the driving force behind the modern liberal state's investment into the development of assets that the private sector would not be capable of producing creates considerable positive effects. For example, investment into scientific research, infrastructure, and education produce considerable value, particularly economically, through the cultivation of knowledge, skills, and productivity of workers, but also reduces illness and disability (Starr, 2007). However, others argue that this heightened intervention is not beneficial to citizens of liberal governments, providing a significant deterrent to personal autonomy and detracting from economic productivity (Batavia, 1997).

Liberal theory is capable of supporting policies that promote progressivism and an activist government, and yet it can also endorse other policies that provide a check on

government by protecting individual freedoms. Both concepts of positive and negative liberty are useful for analyzing the scope of this theory. John Locke provides a foundation for discourse over the role of government in relation to these opposing perspectives, which he accomplishes largely through his articulation of the social contract. He argues that limited government with robust property rights that concentrates on securing negative liberty is supported and has come to be synonymous with classical liberalism. Modern liberalism, on the other hand, adheres to the same premise of limited government that drives the classical form, yet with a deliberate reinterpretation for the purposes of enhancing citizen's positive liberty. In his first principle, Rawls argues that all citizens have a right to basic liberties (e.g., voting rights), while he expands the role of government beyond that of the classical variety with his second principle of justice to encompass social and economic protection of citizen's rights to equality of opportunity and from unwelcomed inequalities. Through these positive and negative aspirations a common theme emerges. Liberty in the form of personal autonomy becomes significant both through negative protections in a classical scheme, as well as positive constructions endorsed by modern liberals. Personal autonomy is both preserved through one's formal rights to pluralistic life choices, as well as affirmed through substantive rights to opportunity and security. Liberal devotion to personal autonomy demonstrates parity with the motivations of the IL paradigm, which advocates to this end by promoting self-direction and respect over dependence, and as a result its pertinence to the social issues of the disability community. Despite numerous historical as well as current failures with regards to protection of citizens with disabilities by liberal governments, the common prioritization of a respect for individual autonomy represent potential for the transformation of theoretical promise to practical application.

IV. EXAMINING DISABILITY IN LIBERAL THOUGHT AND POLICY

The Independent Living Movement consisted primarily of older adolescent and younger working age severely physically disabled individuals living in academic communities. These individuals were motivated by a desire to live fulfilled lives within an able-bodied world and influenced by professionals' desire for people with disabilities to achieve vocational goals (DeJong, 1979).

The essence of the IL movement is the Independent Living Paradigm, which is the analytical manifestation of this movement stating that the problem commonly associated with disability is not necessarily located within the impaired individual, rather it is the environment the individual is located within, often including the solutions offered by medical professionals. As the defining philosophy of the IL movement, one of the IL paradigm's most significant points of emphasis is the equal standing of people with disabilities to those that are able bodied in terms of personal autonomy or sovereignty (DeJong, 1979). The IL paradigm rejects the empowerment of physicians and practitioners to positions of unquestionable decision-making authority which is common place in the medical field, instead finding dependency to be a contributing factor to the inconveniences of disability (White et al., 2010). The IL paradigm insists on society's respect for the resourcefulness of people with disabilities to acquire necessary services and to be granted the opportunity to take risks and make mistakes in the pursuit of their personal conception of a good life, rather than to have policy dictated to them (Fleischer & Zames, 2011). Policies are encouraged that espouse person-centered governmental support that do not promote reliance (Batavia, 1997).

Recent dedications to person-centered planning is consistent with this sentiment favoring autonomy (Medicaid Program, 2014). While the Civil Rights Movement and other social justice movements of the 1960s greatly shaped the IL movement through the emphasis on civil and benefit rights (Scotch, 2001b), as did the consumer movement in its belief in consumer responsibility and self-reliance (DeJong, 1979). Though some attempt to empower through proposals of interdependence in the form of skills training to access to social capital, an emphasis on consumer sovereignty is also seen in the IL paradigm's understanding of people with disabilities as being knowledgeable about their own needs, and deserving a voice in determining the consistency and design of the services provided to them, and their futures in general (White et al., 2010).

The dedication to autonomy seen in the IL paradigm is also observed in liberalism. Some of the most significant and often cited liberal beliefs are: wide dispersal of power, authority through democratic principles and elections as opposed to arbitrary means, and the pursuit and preservation of individual freedom (Cochran & Malone, 1999). Liberalism informed by democracy proclaims the equality of human beings before the law, specific rights endowed to all citizens, and the freedom to pursue their vision of the good life through private and public means without fear of governmental intrusion (Smith, 2014). Each of these characteristics underscore the empowerment of the individual.

The objective of this chapter is to demonstrate that liberalism is capable of assisting people with disabilities seeking membership in an inclusive society and maintaining its values and view of respect. Liberalism has historically ignored, or set aside, people with disabilities in the formulation of its philosophy, however recent liberal theorists demonstrate theoretically

consistent opportunities for the incorporation of people with disabilities in a manner that does not resort to paternalism but respectfully addresses this population's need for accommodation.

A. **Liberal Theory and Disability**

Theory is an essential component of any political redress to the current disconnect between the promises of liberalism and the positions of people with disabilities in today's society. The complex nature of disablement and its relationship to liberal theory in terms of consistency in laws, policies, and practices necessitates a theory based approach to any attempted resolutions (Rioux & Valentine, 2006). However, considerations of people with disabilities are largely excluded from philosophical and theological traditions (Gracer, 2003). This propensity for exclusion in matters of theory in philosophy and law has contributed to the marginalization of people with disabilities (Silverstein, 2010). Exclusion in this manner flies in the face of liberal thought, which values inclusiveness regardless of differing conceptions of a good life (Francis & Silvers, 2007). The omission of people with disability from central concern within liberal discussion is due in large part to the nature of social contract theory, which is a central component to many theories of liberalism. If people with disabilities are to obtain their desired position of parity in most liberal societies as currently and popularly formulated, they will need to demonstrate a logically sound theoretical integration into social contracts.

One of the more significant theoretical omissions of people with disabilities, particularly with respect to liberalism, is that found in the Rawlsian tradition. Similarities between liberalism and the IL paradigm point to a fairly straight forward adaptation to create a cohesiveness between these two philosophies, but numerous nuanced methodologies have incorporated complications of the social contract theory in addressing disability. People with disabilities

complicate Rawls's use of the social contract causing him to ultimately elect to resolve this tension by excluding them from the discussion altogether, focusing his attention on more general issues he saw facing liberalism (Malhotra, 2006). Rawls specifically identifies people with disabilities as existing outside the realm of his theory of justice, stating that he will assume that all relevant and applicable parties possess "physical needs and psychological capacities within the normal range." He goes on to argue that consideration of this population would lead "us to think of persons distant from us whose fate arouses pity and anxiety" (Rawls, 1999, pp. 83-84). Needless to say, this is a problematic and potentially dangerous assumption when viewed from an IL paradigm perspective, the implication being that liberal governments should view people with disabilities as inherently destined for a life of destitution (Malhotra, 2006).

In addition, Rawls (1999) believes that society consists of certain primary goods, or things that any rational person should desire, possession of which allows for the attainment of all other goods in society. He distinguishes between two types of goods. According to Rawls that society plays a great part in distributing *primary social goods* and the manner of this distribution is one factor relevant to his understanding of social justice. Those goods that play a lesser role he calls *natural goods* (Rawls 1999, p. 54). Viewing society through the perspective of those possessing reason and the two moral powers, Rawls bases his conception of primary social goods on the needs of the able bodied. The theory of justice only concerns itself with a just distribution of primary social goods such as, "Liberties, opportunities, the social bases of self-respect, and income," and denies any obligation to address the natural goods of liberal citizens. Disability falls under the category of privations in natural goods with examples such as, "health and vigor, intelligence and imagination." Rawls's theory does not recognize these privations as justification

for the obligation for any corrective social action, and as a result, people with disabilities are at a significant disadvantage on this popular liberal theory, specifically in terms of their opportunities for advancing their social station.

Rawls's exclusion materializes through his beliefs that all morally relevant citizens must be able to comprehend the principles governing society and his need to foster cooperation amongst people with varying abilities and levels of contribution (Hartley, 2009). This he accomplishes by limiting members of society to those possessing reason and the two moral powers: the ability to pursue a rational conception of the good and the capacity for justice. Therefore, to bring liberalism into line with IL paradigm, the theoretical requirement of comprehension that necessitates reason and the two moral powers, in addition to the emphasis placed upon unattainable levels of contribution, must both be addressed by the disability community.

1. **Remedy of dependency**

The inability of a foundational modern liberal theorist such as Rawls to incorporate an entire segment of the population under his umbrella of rights and liberties afforded to all citizens causes some to contend that the only remedy is to scrap the liberal experiment in favor of more communitarian elements (Batavia, 2001). The liberal scheme of government embraces interventions into society for the purpose of addressing the incapacities of individuals, even those with disabilities (Ball, 2000). However, many suggest that the liberal interest in personal independence and individuality serve as the antithesis to social cooperation, and thus must be amended. This sentiment is found in the push for an *ethics of care*, which embraces and aims to bring out the benevolence of relationships of dependence as the basis for

social interactions (Kittay, 2011). This view asserts that a truly fair system would not be founded upon negative liberties, which are only appropriate in the absence of inequalities. Instead, positive liberties and entitlements are justified on the basis of individuals' responsibilities to others and the acknowledgement of dependencies. Those advocating an ethics of care argue specifically that individuals' claim to justice comes, not through rights based on mutual advantage or the possession of certain powers, but through relationships of dependence (Hartley, 2011). Unlike social contract theories, it fosters cooperation through providing for those that provide for others. An ethics of care attempts to recognize that all individuals are vulnerable and dependent to some extent and resources should be provided to those that care for the dependent. It is meant to contrast systems based on justice and rights, which are seen as comprised of universal and objective principles, as opposed to motivations of a personal and emotional nature that typically exist within care-based relationships (Rummery & Fine, 2012).

While proponents wish to see these concepts incorporated into constitutional documents, many disability advocates oppose this philosophy, seeing it as in opposition to the empowerment of people with disabilities by accentuating their dependency and emphasizing a type of care that is notably controlling and paternalistic. Furthermore, protections for caregivers run the risk of eliminating the most desirable elements of caregiving. In attempting to protect caregivers through public support or professionalization, one potentially sacrifices the personal and emotional motivations of many care relationships. This would transform the foundation of care-based relationships to being less concerned with "caring about" and more towards the less empathetic "caring for" form (Rummery & Fine, 2012). Some consequently advocate a more tempered position whereby both sides are respected. This materializes through a right to social

participation for all, resulting in the public recognition of the role the caregiver plays in facilitating this right. However, such an amendment to an ethics of care refocuses the emphasis from the promotion of a duty to others to individual liberties, which ultimately and unmistakably returns once again to yet another liberal iteration.

2. **Finding space for liberals with disabilities**

The standards of citizenship typical of the current liberal formulation within the US are particularly prejudicial and exclusionary towards the disabled. A theory-based examination into liberalism articulates a methodology for reforming the current understanding of liberalism that is not mindful of the capabilities of people with disabilities. This examination of liberal theory demonstrates that its history of exclusion of people with disabilities comes about as a result of misinterpretation of core elements, resulting in hyper-exclusionary ideas of citizenship. The following approaches lay out the logically sound execution of liberal principles in manners that produce standards widely attainable by people with disabilities.

It is argued that by simply eliminating the distinction between social and natural goods much would be remedied by way of access to equality in the disability community (Malhotra, 2006). Through this amendment, natural goods, and their associated disabilities, would be within the purview of public accommodation. Another path to integration would be to identify people with disabilities as the least advantaged within society, thus justifying their receipt of redistribution according to the difference principle of the theory of justice. While each of these solutions are certainly amongst the most obvious alterations, they alone would not produce the desired effect. The former solution regarding the classification of natural goods is merely an issue of semantics. It makes no difference whether Rawls's (1999) theory specifically identifies

accommodations or if one is provided with the requisite primary social goods as compensation for the effects of natural disability. As for the latter solution, it can be argued it would only risk further stigmatization and ignore the effect of social barriers, but would ineffectively resolve all of the complications of integrating people with disabilities into the social contract (Malhotra, 2006). Neither of these posited solutions address what has been identified above as the sites of exclusion in the social contract. An effective solution for inclusion must resolve the emphasis placed upon the requirement of cognitive functioning and the issue of contribution disparity.

A more apt theory-based solution addresses the exclusion of the disabled at the point of the social contract. This issue of social contracts poses an obstacle to liberals with disabilities. Hartley (2011) identifies two distinct types of social contract theories. One form is Contractarianism under which society is believed to come together to form a collective on the basis of its mutual advantage to benefit each individual. Thus, individuals are seen as free to negotiate and formulate rules for society based upon whatever each party agrees to be personally advantageous. Although people are viewed as existing only within the normal range, and thus, roughly equal in terms of their physical and mental abilities, they are, however, free to negotiate the terms of the association through levying their individual skills and talents to their own advantage. This opens the possibility that the agreed terms be skewed to the benefit of those parties with the greatest skills and talents, given the least fortunate stand to benefit most from being in association with the most fortunate rather than in competition with them (Hartley, 2011). Though this mutual advantage methodology leaves open the opportunity for individuals of great abilities to bargain to the benefit of people with disabilities, social contracts based upon

mutual advantage are a largely uncomplimentary strategy for obtaining rights for the disabled as their prospects in life are greatly contingent on the will of the most advantaged.

On the other hand, contractualism is another form of social contract where society is formed on the basis of mutual respect for the freedom and equality of one another. The terms of such an association must be agreed upon by all parties or their representative, and as such, members of the resulting contract are typically required to possess the ability to pursue a rational conception of the good and the capacity for justice. Cooperation according to mutual advantage requires that all parties benefit beyond their initial position, whereas reciprocity only requires that each party consents to the terms of cooperation. This means that cooperation according to social contracts based upon reciprocity and mutual respect have no minimum contribution requirement (Hartley, 2009). This perspective only permits the acceptance of a conception of justice that produces equality for all. On this view, only a conception of justice and terms for society would be accepted by free and equal citizens that are based upon the notion of reciprocity (Hartley & Watson, 2010). The effects of grounding society in a social contract based upon reciprocity and mutual respect is the reduction of social hierarchies of domination and subordination, and the creation of social conditions necessary for respect.

As each is a form of contract theory, they both espouse a means of binding individuals to a system of cooperation, yet the impetus for this engagement varies between the different forms. On contractarianism cooperation is brought about through the mutual advantage that individuals gain through the benefits created from the contribution of the skills and talents of multiple parties according to the terms that are accepted. Contractualists, on the other hand, reject mutual advantage in favor of the reciprocity that occurs when parties have respect for the freedom and

equality of each other. Rawls, it is argued, utilizes a largely contractual hybrid of these two forms, using mutual advantage and the view that individuals should be seen as roughly equal for the purposes for selecting principles, both of which are contractarian, but also the two moral powers, which are contractual (Nussbaum, 2006). It can be argued based upon amendments that he later made to the circumstances of justice in his theory that Rawls (1999) preferred contractualism (Hartley, 2009). Nevertheless, this hybrid form neglects any specific resolution to a manner of inclusion for people with disabilities, which leaves readers, theorists and policymakers free to allow popular misconceptions to characterize their understanding of the rights and duties of people with disabilities and society.

Despite this foundation in respect and reciprocity found in a contractual form of social contract theory, the citizenship requirements put into place by Rawls (1999) limit the benefit of liberalism experienced by people with disabilities. Rawls asserts that liberal citizens must be within the normal range and fully cooperating. Hartley (2009) finds this to be at odds with the motivations of contractualism as many people with disabilities are capable of fully participating and cooperating within society without the normal range of human capacities when provided appropriate accommodations. For example, a central liberal component is autonomy, which can be seen as implying certain cognitive capacities. Despite this ostensive exclusion of people with intellectual impairments, liberalism is capable of incorporating citizens with intellectual disabilities as well through simple accommodations. The utilization of a proxy for decision-making purposes when necessary allows these citizens to participate in liberal society without detracting from core principles (Francis & Silvers, 2007). Instead the social structure of society plays a greater part in determining opportunities for participation (Hartley, 2009, p. 25). Given

contractualists avoid cooperation requirements concerning levels of contribution, people with disabilities must simply show a capability of participating in society's institutions regardless of economic contribution. This means any broadly interpreted level of cooperation by people with disabilities within social and political institutions could replace the popular conception of a citizenship requirement of significant participation within the economy; a more inclusive standard of citizenship. Even participation by way of one's capacity for engagement could suffice, demonstrated through contributions to such institutions as the family or social relationships (Hartley, 2009). This view of reciprocity, in addition to reforming the requirement of the comprehension of governing principles of society satisfactorily addresses all stated social contract barriers to people with disabilities. This shows that, while multiple formulations of society are possible, any citizenship limitations regarding human abilities are unnecessary and arbitrary.

Some argue that this solution based upon reciprocity situates people with disabilities as second class citizens. Given their participation disparities with able bodied citizens, some see this view as premised upon an unrealistic view of human nature and rationality as, it is argued that, no party would consent to such selfless contractual terms. Where the above articulations of social contracts are based on mutual respect and advantage, Sisson (2015) advocates for a broader sense of advantage. Where a contractarian intends to produce a maximum mutual advantage for each party, through a focus on cooperation through the contribution of peace and sociability, participation is narrowed to a minimum mutual advantage by isolating the most basic level of human cooperation. Rather than viewing individuals as choosing society for its personally advantageous properties, society is seen as advantageous solely for its ability to

produce conditions of safety. This refocuses the perspective society would take towards people with disabilities, highlighting their largely nonviolent attributes as opposed to their impairments. The previous two liberal forms and methodologies institute minor reforms creating significant effects for citizens with disabilities. While one emphasized reciprocity, the other focused on the basic advantages of safety and security. Both of these approaches to citizenship were capable of constructing distinctly liberal terms of cooperation that were also formulated in such a manner as to align with the IL paradigm, allowing people with disabilities to benefit from an inclusive liberalism. With the theoretical basis for the incorporation of people with disabilities into society through liberal principles of association established, an examination of liberalism with respect to people with disabilities in practice becomes germane.

B. **Liberalism and Disability in Practice**

The disability rights movement has worked to bring about greater social inclusion and integration of people with disabilities in the US through the Americans with Disabilities Act in 1990 and many legal cases, but advocates of this movement suggest that an inclusive society has not been created despite the stated goals of its dominant political philosophy (Burch & Sutherland, 2006; Fleischer & Zames, 2011; Francis & Silvers, 2007). Social barriers to inclusion prompt disability advocates to critique the opportunities that have been made available to people with disabilities within the liberal US government (Barnartt, Schriener, & Scotch, 2001). For an inclusive US society to be experienced by the disabled, they must be engaged in an open and authentically deliberative political process to bring about participatory parity through a just level of social arrangements (Knight, 2015). Such an arrangement inevitably calls for governmental interventions creating a substantive ability to exercise formal rights (Batavia,

1997). However, measures promoting positive liberty, such as universal insurance programs require mandated enrollment of federal assistance programs that necessitate heightened taxation for services that benefit some individuals more than others. These types of programs require a reciprocal sacrifice of negative liberty (Rooksby, 2012). While devaluing personal autonomy contradicts the fundamental principles of the foundational IL paradigm (DeJong, 1979), the significant disparities of people with disabilities in the US also opposes the central liberal principle of equality. The balanced nature of liberalism between its elements of both positive and negative liberty cause some to argue that a liberal scheme of government must be scrapped in order for many groups to finally obtain the opportunity for inclusion (Russell, 2002).

1. **How liberalism fails disability today**

Though liberalism asserts the equal right to freedom, it has sanctioned discriminatory practices with respect to certain groups categorized by race, gender, or other identifying characteristics resulting in numerous social movements (Starr, 2007). Advocacy in regards to these practices has been articulated by many in the disability community since the latter third of the 20th century, and is the result of an *empowered consciousness* brought about by the acute awareness these individuals have developed regarding the mistreatment their community has and continues to experience within the US' liberal public philosophy (Charlton, 1998). While much has been gained by the disability community in the past few decades, the 2nd class status of people with disabilities remains today as this community has yet to experience the liberty promised to liberal citizens and achieved by the social movements of many other groups (Turnbull, 2012).

Often times, a propensity toward the negative liberty side of liberalism is attributed as the primary cause of the disparate status of people with disabilities in the US. This propensity is seen in the centrality of the market to liberalism, and within American society in general. Relevant to this aspect of liberalism is libertarianism and neoliberalism. Libertarianism is a subgroup group of the liberal ideology holding extreme stances regarding the liberal belief in limited government. Libertarians regard inequality as a product of state interference into the natural effects of the free market. In place of regulatory measures, libertarians prescribe market-based solutions, private insurance and charitable giving as solutions to social ills (Arnold, 2009). The libertarian philosophy sees equality only in terms of a right to liberty in an exclusively formal sense. It is committed to the belief that rights have no merit if they interfere with individual liberties outlines the primacy of the market. Thus, libertarians' view rights solely in terms of their ability to protect private property and those that infringe upon this ambition are removed (Oakes, 2005). Neoliberalism is the term, often used pejoratively, to denote this mode of policy making, particularly its effects with regards to creating inequality and causing the opting out of the rich within society (MacGregor, 1999). It strives to promote policies that reduce governmental involvement and control over the dealings of citizens, believing that private citizens are empowered through their ability to engage in the market. This strategy is the preeminent global policy perspective, with no alternatives being significantly explored. Furthermore, it is also believed to have contributed to historical financial crises, including that of 2008 (Centeno & Cohen, 2012). Synonymous with the key figures of Margaret Thatcher in the UK and Ronald Reagan in the US, these social policies originated in the 1970s, emphasizing a

policy strategy of trickle-down economics and supported by beliefs in personal responsibility and limited government (MacGregor, 1999).

One of the barriers to the inclusion of people with disabilities within liberal society most relevant to these policies is through the area of employment. A neoliberal form of social service delivery addresses disability through charity and the market. Many liberals conflict over neoliberal approaches to policy making (Arnold, 2009). Due to this heightened market environment consistent with neoliberal policies, citizens with disabilities are inherently disadvantaged, placed in the center of the debate concerning the property rights of the majority and the proper social desert of others. Related to this debate is the idea of citizenship. This concept defines the boundaries of society, designating the particular qualifications necessary to be present within an individual for him or her to be regarded as a member of society, and as a result, which individuals should be allowed to reap its benefits and who should not (Rioux & Valentine, 2006). The neoliberal system of social policies champions a certain set of characteristics supporting the notion that success is to be determined on the basis of merits. Some argue people with disabilities are used to reinforce these able-bodied norms and transform them into commonplace qualifications of citizenship. The concept of *ablenationalism* describes how people with disabilities are seen as simply patient-consumers with minimal buying power through neoliberal principles of economics, and thus they are in turn marginalized for the purposes of reinforcing certain value systems and ideals. Through this marginalization, people with disabilities are labeled “deserving poor” and too impaired to work in exchange for certain minimal services and charitable donations. Their marginalization supports and props up the conventional norms of market capitalism, such as the values of competition, physical fitness and

determination (Snyder & Mitchell, 2010). Using people with disabilities in this means is intended to derive more utility than they are seen as having in the market and a capitalist society, which sees them as lacking purchasing power and simply as patient consumers (Russell, 2002; Snyder & Mitchell, 2010).

Insofar as neoliberal policies support capitalist principles, they afford social and political power to the owners of capital, causing economists on the left to argue that these power centers recognize the supply-side advantage to the preservation of a certain level of unemployment, causing increased labor competition, which supports low wages and allows for the opportunity for higher profit margins. This, coupled with the fact that the disabled are often designated the least desirable employment candidates and the first to be let go despite their merits, places them in a position of considerable reliance upon and affected by the national employment rate. That a neoliberal system requires the disabled to be dependent on employment for the attainment of basic services, inevitably causes them to be disempowered in terms of their ability to achieve their personal conception of a good life (Russell, 2002). Therefore, through both of these instances, one can see how neoliberal characteristics can be used for the marginalization and suppression of the disabled, rather than for the promotion of social justice and the reduction of inequality.

Related to employment barriers, another cause of the disparities between disabled and non-disabled citizens within the US is the lack of PAS provisions. One cause of the disparity these individuals experience in locating and securing employment is the current policy scheme which disincentivizes employment for people with disabilities. When these individuals do successfully obtain employment they often lose supports necessary to their health and

independence including PAS, Medicaid and Medicare. Consequently, if Americans with disabilities have jobs, they are typically only marginal positions and if they do not have jobs, most likely they have given up searching (Fleischer & Zames, 2011). Further complicating this employment disparity is the volatile nature of the PAS provided to many people with disabilities. Administrators of PAS programs use various assessment scales to ascertain the dependency level of each applicant before awarding the select few deemed worthy of services (Scotch, 2001a). These assessment tools place program participants in a precarious position as a result of being in a constant state of potential service denial or reduction. The implications of service denial are quite severe for individuals desiring to maintain an autonomous status as many clinicians see the likelihood of providing a person-centered approach to care in a clinical setting as minimal (Vladeck & Westphal, 2012). Many individuals are also at risk of losing their independence without losing beneficiary status, but simply through the trends of policy reform. Many US states are adopting Medicaid Managed Long-term Services and Supports (MMLTSS) to slow the ever increasing cost of healthcare. The aim of MMLTSS is to create efficiencies in healthcare through the strategies of reducing management entities to consolidate the decision making authority, restrict consumer choice to specific providers and substitute lower cost interventions (NCD, 2013). Streamlining services in this manner minimize the ability of these programs to effectively address the diverse nature of disabilities in terms of the many levels of abilities and various preferences. Public programs carry inherent assumptions regarding the nature of disability and what it is to be human (Scotch, 2001a). The characteristics of the current PAS offerings within the US directly contradict a liberal understanding of enabling people with disabilities to be fully human, which is enabled through control over these services (Mladenov, 2012). These policies

not only contradict the IL paradigm in their disregard for personal autonomy exemplified in opportunities for self-direction in PAS, but also the core liberal principle of an equal right to personal freedom.

C. **A Shared Dedication to Empowerment**

The ability of liberalism to empower people with disabilities remains the question at hand. The examination of the theoretical foundation of liberalism showed that its core principles are certainly conducive to this possibility, particularly through social contracts based upon reciprocity or the prospect of a safe and peaceful society. Despite this possibility, disparities in opportunities for employment or the provision of services needed for basic human functioning call the likelihood for empowerment of citizens with disabilities under a liberal scheme of government into question. However, much of these disparities are brought about through neoliberal policies, as opposed to liberalism in a broader sense. Regardless of current social injustices, this examination has demonstrated that the social circumstances of impairment require a nuanced approach. This balance between the freedom of the private sector and the collectivity of public ventures is a central feature of liberalism (Starr, 2007). The above similarities between IL paradigm and the principles of liberalism demonstrate a shared dedication to empowerment. Without exclusion of people with disabilities from theoretical approaches, this shared ambition comes to light. Citizens with disabilities are empowered by honoring their basic rights to positive liberty and harnessing economic forces to work toward the general welfare. In these ways, modern liberalism, as well as many principles typical of its classical form, are each capable of enhancing the position of citizens with disabilities in ways that complement the IL paradigm, and as a result, benefit this segment of the population. While modern liberalism emphasizes positive

liberty and classical liberalism focuses on limited government and the use of market forces, each form employs both strategies to varying degrees. Combined, liberalism is the political philosophy within which a disability minded political agenda can be advanced most successfully.

1. **Positive liberty through public interventions**

Through the provision of rights and services, liberals believe that, not only are citizens better able to access personal freedom than simply through negative liberty or restrictions against the government, but that it is an obligation of liberal governments affirmed through one of its most renowned expressions, the US Constitution. Negative liberties, while potentially contributing to a particular end or good, necessarily lack a practical product; they represent the absence of directly resulting purpose, while positive liberties do indeed possess objects or direct intentions. As a result, it seems nonsensical to argue that the purpose of liberal government, as discussed in the Preamble of the US Constitution, is solely to protect citizens from the government. On the other hand, positive liberties can be spoken of in the sense of being a purpose of government, whereas negative liberties, no matter how beneficial to citizens, cannot (Barber, 2007). This argument for the purpose of government rings true universally for liberals to different extents, with the exception of a portion of libertarians who argue for extreme limitations on government (Batavia, 1997).

On a Lockean understanding of liberalism, one chooses to step out of the state of nature and enter into association with others on account of the benefits awaiting the individual through membership. Compared to the relative uncertainty that exists outside of the protection of the State, government is born out of one's desire to protect his or her property (Locke, 1694). Thus it can be seen that the impetus for the State is the accommodation of the incapacities of man. Once

an association based upon incapacities has been created, the only question that remains is to determine which positive liberties are to be deemed permissible. The breadth of positive liberty allowable under a liberal construction must account for the needs of people with disabilities when one takes into account its foundational aspirations (Ball, 2000). To deny people with disabilities the rights and services that their impairments require to protect one's right to pursue their individually scripted conception of the good would be a blatant contradiction (Francis & Silvers, 2007). Therefore, positive aspects of government are not only unavoidable, but created specifically for the purposes of the amelioration of the needs of human beings, not unlike those experienced by people with disabilities.

2. **Market-based empowerment**

A classically-minded liberal method for empowering people in general is through the harnessing of the power of market forces. Despite the contention that classical economic principles lead to social unrest, they have held on to their prominence, having reached a level of global influence since the end of the Cold War with no significant alternative being realistically pursued today (Centeno & Cohen, 2012). Often such a liberal economic system is not seen to benefit people with disabilities. It is argued that these citizens are further disabled through these policies, particularly an emphasis on competition in the economy. This competition is often viewed to have negative effects for workers in general through wage suppression, particularly so for the disabled as they are seen to be inherently disadvantaged through this enhanced competitive environment (Russell, 2002).

Classical economic principles, namely increased competition and the minimization of barriers to enter the market are typical of right leaning liberals. This iteration of economics can

be read with a more egalitarian flair than typically interpreted. This system is beneficial normatively as well as practically due to its similar aim to redistributive policies that take wealth from the affluent to those in need. This culminates in a progressive-like objective, specifically the minimization of inequalities. However, this system uses pre-distributive economic policies, which prevent the concentration of large amounts of wealth all together. The misconception within the common interpretation of this system is that these principles keep rates of profit low and restrict monopolization of the market through increased labor competition. Not only does his understanding of the market call for increased labor competition, but also heightened economic competition overall, produced through the reduction of barriers to the market (Boucoyannis, 2013). The implementation of increased competition and the reduction of unnecessary barriers to the market is meant to benefit society as a whole, not any single group or protected class. Additionally, a productive and vibrant economy based on principles of efficiency is needed for the financing of disability related costs, including the above public interventions. When compared to poor countries with insufficient resources, people with disabilities benefit from the productivity of wealthy economies and are in turn equipped to contribute to the economic production through the services and supports it affords. Sacrificing efficiency weakens economic production, the ability of the state to address disability issues, as well as the ability of people with disabilities to make economic contributions and achieve inclusiveness within their communities (Batavia, 2001). This result can benefit the disabled by protecting personal autonomy and preserving the affordability of goods and services without resorting to paternalism. Complete removal of this population from market capitalism, would require the acceptance of a label of permanently oppressed, coming at the cost of self-identifying as

powerless and victimized. This additional label would add to barriers created by discriminatory attitudes and misconceptions contrary to the empowering ambitions of the IL paradigm (Batavia, 2001). Respect for smaller, individualized solutions wherever possible is a benefit of a liberal market-based approach. The diversity of the disability community, particularly in terms of their various impairments and their associated manifestations warrant a similar variety in the proposed interventions and policies of the government (Scotch, 2001a).

As discussed above, people with disabilities largely experience inherent disadvantages in the employment market characteristic of a liberal society (Snyder & Mitchell, 2010). Due to this marginalization, publicly funded interventions are often the only recourse for addressing the inconveniences of disability, whether it be through the prohibition of discrimination or redistributive efforts. First, oversized state funded projects, no matter how well intentioned, bear the potential for creating dependency, which is the antithesis of any recommendation made through the IL paradigm, or liberal theory for that matter (Batavia, 1997). Second, the large bureaucracies created out of these policies are often less capable of meeting the individualized needs of members of the widely divergent disability population, disregarding the personal preferences of individuals in favor of a paternalistic vision for participants as a whole (Scotch, 2001a). Lastly, these large bureaucratic systems often institute gatekeeping standards, which pose additional potential for marginalization, including poverty requirements and the creation of disabling self-perceptions. These ostensibly objective testing systems separate those in need, often requiring the acceptance of a poverty status and an oppressed minority label to obtain necessary funding or services (Barnartt, Schriener, & Scotch, 2001).

A policy agenda is needed that recognizes the fundamental necessity of personal autonomy. These interventions, in maintaining their liberal nature, seek the collaboration of multiple stakeholders including the individual with a disability and his or her family, the private and public sectors as well as the support of the American people, all while striving to uphold the highest ambitions of the disability community exemplified in the IL paradigm (Batavia, 1997). This is not to say that the state is justified in believing people with disabilities should be left to fail in a system in which they are inherently disadvantaged, but rather that a liberal blend of public interventions and market-based solutions are necessary to ensure the disabled community has access to the greatest level of personal autonomy and is thus optimally empowered.

D. **Political Opportunities**

Aside from a vocal subset of liberalism called libertarianism, much of the liberal US political landscape presents opportunities for the implementation of a disability-minded policy agenda consistent with the positions suggested above. In terms of the political landscape in the US, shared positions between each of the major political parties and the views of the disability community encompassed in the IL paradigm demonstrates cause for promise. Given its lack of significant impingement upon the market economy and reluctance to create governmental dependency in the form of redistribution or large social service bureaucracies and its bipartisan nature, the Americans with Disabilities Act of 1990 is a prime example of liberal disability policy (Batavia, 1997). Molded after the Civil Rights Act of 1964, the ADA addresses discrimination in employment and issues of access to areas of society, such as buildings, transportation and goods and services. While the ADA does not engage in affirmative action policies in that it does not mandate employment positions for people with disabilities, it does

ensure certain employment related rights to reasonable accommodations and protections against discrimination (Dowler et al., 2011; Fleischer & Zames, 2011). It utilizes a view of care-based relationships as an exchange of services between rational actors as opposed to an elective act engaged in to satisfy particular sentiments (Kittay, 2011). This manner of attending to social and attitudinal barriers associated with disability in society demonstrates that the ADA represents a unifying point between liberalism and the disability rights movement (Ne'eman, 2009).

The political Left's stance that government ought to address equality of opportunity, or individuals' access to the full scope of society regardless of characteristics or starting position, and attempt to create full participation of marginalized groups is shared by those that follow the IL paradigm. However, the Left has yet to make disability issues central to their platform compared to other social movements and often supported practices such as euthanasia, assisted suicide, and elected abortion, which are abhorred by people in the disability community. The Right, on the other hand, generally detest such practices on moral grounds, specifically social and religious conservatives. While people with disabilities sometimes oppose religious stances due to the manner that many religions account for disability, those that follow the IL paradigm agree with these moral positions despite their premise. The Right also opposes the creation of large bureaucratic service systems, which is a position shared with the IL paradigm, though their perspectives likely differ regarding its premise as the Right is less likely to be concerned with policies to protect the personal independence of people with disabilities than the effects costly programs have on the personal independence of the general public (Batavia, 1997; Ne'eman, 2009). Aside from a small portion of libertarians, many conservatives recognize the need for public interventions that provide assistance to people with disabilities, albeit on moral grounds

(Arnold, 2009). With its similarity to other social movements (e.g., the Civil and Women's Rights movements), as well as its original adherence to principles of self-help, self-reliance and personal responsibility, the advancement of the disability agenda has some appeal to both sides of the political aisle overall. Liberalism possesses the proper tools to partner with the disability community to bring about successful policy, which includes: partnership between the disabled individual and the public and private sectors, while effectively maintaining the autonomy of people with disabilities.

A dedication to personal autonomy within an Independent Living framework aligns with a similar focus articulated by key liberal theorists. Past neglect of the citizenship of people with disabilities within liberal theory, in addition to other current and historical injustices, can reasonably lead to a belief that liberalism is incapable of accommodating this segment of the population. Despite exclusion from influential theories, such as that of Rawls (1999), Hartley and Sisson (2015) articulate a capacity for cogent reinterpretations of liberal theory that successfully extend citizenship to people with disabilities. However, a shared understanding of human autonomy as a fundamental right shows that, despite the limited inclusion of disabled people as a category in the application of liberal theoretical principles, liberalism is capable of falling into line with the IL paradigm. Consequently, liberal theory has the potential to be a resource through which policy that operates on a respectful and responsible understanding of all embodied differences can be developed. As a result of this potential, liberalism becomes a prism through which to examine disability policy, in other words, to what extent are liberal principles apparent in existing disability policy. To that end, the following chapter will utilize this guide in assessing the HCBS policy systems within Illinois and Wisconsin.

V. COMPARISON OF MEDICAID LONG TERM SERVICES AND SUPPORTS IN TWO STATES: ILLINOIS AND WISCONSIN

The balancing of the US LTC system is a priority for people with disabilities as well as policy makers, but conducting this reform according to a liberal framework is just as critical. Within US policies there exists an institutional bias against the provision of LTSS in a community-based setting. The US has begun the process of rectifying this barrier to independent living through an emphasis upon the creation of and community access to HCBS, though the bias has not been eliminated (Fleischer & Zames, 2011). This endeavor into the deinstitutionalization of Americans with disabilities must be contained within a liberal framework so as to ensure a nuanced service implementation that provides greater opportunities while preserving the personal autonomy of these citizens.

Both Illinois and Wisconsin represent excellent objects of analysis from a perspective of liberalism. While, each of these states share a border, they have vastly different HCBS systems. Illinois has a relatively open system with only one significant publicly funded personal assistant service (PAS) program to serve its adults with physical disabilities under the age of 60, whereas Wisconsin has been far more active and forward thinking with regard to its HCBS policies, developing a larger network of programs. Wisconsin offers eleven waivers to direct public aid toward those requiring HCBS. This chapter will situate the service systems of these two states within a broader national context and address the intricacies of the Illinois Home Services Program and the following six Wisconsin-based programs, all seven of which pertain to adults with physical disabilities: Community Integration Program II Waiver (CIP II), Community Options Program Waiver (COP-W), Family Care, PACE, Partnership and IRIS. Through this

examination, the reader will gain a greater understanding of the practical realities of a liberal framework for state service systems.

A. **The United States Long Term Services and Supports System**

Long Term Services and Supports (LTSS) describes home or institutional-based services and supports typically used by individuals unable to perform certain essential life activities. These services are intended to aid in creating personal independence (O'Shaughnessy, 2014). Some estimates indicate 11 million adults receive LTSS (Kaye, Harrington & LaPlante, 2010). In 2012 these services made up a total expenditure of \$219.9 billion (Martin et al., 2014). Private insurance policies covering long-term care services are typically expensive and provide insufficient reimbursements (Mendelsohn et al., 2012). Only 7 million Americans hold these policies, as a result out-of-pocket spending accounts for only approximately 22.4% of total LTSS spending (Gleckman, 2011; Issar et al., 2012; Martin et al., 2014).

Over half of the working-age people with disabilities living in the community are covered by public health insurance (Livermore et al., 2011). While Medicare does not play any role, the funding of LTSS has been relegated to Medicaid, such that it accounted for 61% of all LTSS spending in 2012 (Martin et al., 2014). Public spending to benefit people with disabilities is likely to continue to increase. This likelihood indicates that policymakers are under increasing pressure to use resources efficiently (Livermore et al., 2011).

1. **The reform efforts**

The reliance upon public insurance makes the lack of comprehensive policy addressing the cost for them to live in their homes and have reasonable access to social mobility considerably impactful (Scotch, 2001a). Many attempts have been made to reform the current

LTSS system with more universal and substantial coverage. A bill (U.S. HR 2263) was proposed in 1989 by Congressman Claude Pepper that would have provided insurance coverage for in-home long-term care for all individuals assessed to require assistance with at least two ADLs, however, this bill never came to vote in Congress (Glazier, 2001). The Clinton administration then proposed a PAS entitlement for individuals requiring assistance with at least three ADLs as a part of their Health Security Act, which never came to be law. Another effort was made in 1997 when Speaker of the House Newt Gingrich introduced the Medicaid Community Attendant Services Act (H.R. 2020), also known as MiCASA. The bill was reworked and reintroduced again in 1999 by Senators Tom Harkin and Arlan Specter with the addition of supports for the aged, intellectual disability and chronic mental illness populations (Grossman, 2011).

The Community Living Assistance Services and Supports (CLASS) Act, included in the 2010 Patient Protection and Affordable Care Act, was created to move citizens off of Medicaid through the creation of a national voluntary private insurance program. Participants would be able to cash out payments to purchase long-term care, however, without mandated enrollment or the ability to deny or raise premiums for high-risk populations, it unfortunately suffered from many of the same flaws that plague the current private insurance market for LTC including low demand and adverse selection (Gleckman, 2011; Issar et al., 2012; Kennedy et al., 2016). Despite these obstacles, the true opposition to CLASS concerned its cost. As a result, efforts to present potential remedies to Congress failed and it was removed from the 2012 Health and Human Services budget (Gleckman, 2011; Issar et al., 2012).

2. **Home and Community-Based Services waivers**

Home and Community-Based Services (HCBS) are LTSS that allow participants to live in their home or community, avoiding institutionalization (O'Shaughnessy, 2014). States can access federal funds designated for the purposes of HCBS through two avenues including: Medicaid Personal Care Services Optional State Plan Benefit and Medicaid 1915^(c) Home and Community-Based Services Waivers (Grossman, 2011; LeBlanc et al., 2000). HCBS 1915^(c) waivers are the most widely used LTSS funding source by states throughout the country with 1.4 million participants nationwide according to 2010 data. Programs funded through these means may be no more expensive than its institutional alternative, and only benefit these individuals eligible for institutional placement (LeBlanc et al., 2000; Ng et al., 2014).

The US Census Bureau estimates there to be approximately 39 million non-institutionalized Americans with disabilities (US Census Bureau, 2013). Aside from Arizona, Rhode Island, and Vermont, which use other waivers to provide these services, states provide funding to their residents with disabilities to remain in their communities primarily through 1915^(c) waivers. Medicaid Home Health services also take up a portion of the national LTSS budget. In 2010, the US spent in \$5.7 billion on home health state plan services for 807,659 participants. Nationally, the United States spends \$10.2 billion on personal care state plan services for its 951,853 participants. Cumulatively, these services all contribute to the LTSS system that grants people with disabilities access to independence. Throughout the US there are over 3.1 million participants in 1915^(c) waiver programs (Ng et al., 2014). Lastly HCBS waivers were established to provide people with disabilities other options to institutionalization in their effort to maintain a functional and inclusive life. Being that the 1915^(c) waiver is a state waiver,

the manner in which the waiver is utilized is to some degree at the behest of the state. This means that the waivers are capable of being applied to whichever specific population or geographic region the state designates. It is not required that a 1915^(c) waiver be applied to all categorically or medically needy citizens of that state. The states also have the ability to set the specific need criteria of the programs funded by these waivers, although these need criteria may be no less restrictive than the federal need criteria for institutional placement. Each waiver application also requires the states to designate the number of slots or maximum number of participants to be allowed in the program. Finally, states may select the funding eligibility criteria for these waiver programs to be the same as that of institutional placement, which is up to 300% of Social Security Income.

3. **Program cost**

PAS costs vary widely depending upon the program structure and other variables. One significant variable capable of affecting costs is the intended participant limitations meant to be addressed by the program. Many programs provide PAS to participants for the purposes of addressing his/her limitations with regards to ADLs, but PAS may also be required to provide supervision or stand by assistance (Glazier, 2001). Additional costs may arise if PAS are provided to meet participants' needs regarding instrumental activities of daily living (IADL) as well.

Cost containment is more conventionally arrived at through limitations placed upon service use or through cost caps. Cost caps refer to formal limitations set up within the program at predefined points (LeBlanc et al., 2000). There are two typical forms of cost caps: individual cost caps and aggregate cost caps. The individual cost cap form places restrictions upon a

participant's services in reference to a particular funding amount specific to the participant's service usage. Aggregate cost caps are put into place in reference to the total program cost spread out amongst all individuals' accumulated funding amounts. It is believed that aggregate cost caps are more lenient; allowing certain participants to receive funding for services that exceed the amount they would receive for institutional services (LeBlanc et al., 2000).

4. **Personal Assistance Services models**

The World Institute on Disability provides six delivery models through their examination on the topic. The six models include: the Independent Provider model with medical supervision, Independent Provider model without medical supervision, the Agency Provider model with medical supervision, the Agency Provider model without medical supervision, the High Management model, the Legislated Reimbursement Rate model (Glazier, 2001). In addition to the service delivery model, the PAS management model also affects program cost. The income subsidy model is a PAS management model in that participants of a program in this category receive a specific cash allotment which they are free to use to purchase any and all goods and services deemed necessary by the individual. This model is closely related to the voucher model. This model also closely parallels the cash and counseling model, which provides the participant with a cash allotment to purchase goods and services with the exception that this model also grants counseling services to the participant for the effective utilization of the program. The consumer cooperative model functions such that eligible participants pool their funds together to purchase goods and services. The management choice model, which is modeled after the Pennsylvania Attendant Care Program, allows participants to select the degree of self-

direction and responsibility he or she wishes to shoulder, the remainder of which is delegated to the program contractor provider agency (Glazier, 2001).

5. **Illinois and Wisconsin versus the United States**

There are 1.4 million Illinoisans with disabilities (11% of its population), and 600,000 Wisconsinites with disabilities (12% of its population) (U.S. Census Bureau, 2013). In terms of institutionalization, Illinois had 17,484 residents under the age of 65 living in nursing homes as of 2012 (Health, Education, Labor, and Pensions Committee, 2013). This was approximately a 3% increase since the 16,949 reported in 2008, which was one of the smallest increases in the nation. However, both figures were high enough to place Illinois as the number one state in terms of this measurement for 2008 and 2012 by a significant margin. Wisconsin, on the other hand, had 2,788 residents under the age of 65 living in nursing homes in 2012, also approximately a 3% increase from its 2,703 in 2008. These totals ranked Wisconsin 38th and 33rd respectively in the nation.

The ability of people with disabilities to choose where they reside provides an indication of these individuals' opportunities. In terms of affordability and access, choice of setting and provider, quality of life and quality of care, support for family caregivers, and effective transitions, Illinois and Wisconsin rank 8th and 15th overall nationally (Reinhard et al., 2014). Compared to the national median of 50.7%, Illinois ranks 8th highest in the country with 69.6% of its new Medicaid users receiving care in the community as opposed to institutions, while data with respect to this measure was not available for Wisconsin. The percentage of Medicaid and state funded LTSS expenditure going toward HCBS for elderly and adults with disabilities. Wisconsin ranked 10th in the country with 46.2%, compared to Illinois' 19th with 39.4% and the

national median of 31.4%. Based upon Illinois' favorable ranking with respect to new Medicaid users receiving HCBS but somewhat poor showing in the expenditure category, many explanations are possible. One potential explanation is that Illinois' poor record of HCBS participation in the past is creating a situation in which, now that individuals are being transitioned from institutional settings, a greater percentage of the eligible population is now receiving HCBS. In addition to indicators measuring the freedom of people with disabilities to make decisions regarding their own care, the report also provided indicators with respect to the quality of life of people with disabilities in each state. The percent of people with disabilities over 18 years of age within the community reporting usually or always receiving needed support lends itself to our understanding of the quality of life of people with disabilities across each state. According to this indicator Wisconsin is 6th in the country with 76.4%, compared to Illinois' 15th at 74.2% and the overall median of 71.8% (Reinhard et al., 2014).

B. Illinois and Wisconsin Home and Community-Based Services

In 2010 Wisconsin had 86,052 participants utilizing HCBS waivers compared to 104,701 in Illinois (Ng et al., 2014). Wisconsin spends just over 1.8 billion annually compared to Illinois with just over \$1.3 billion (Ng et al., 2014). As a nation the United States spends approximately 52.7 billion on HCBS waivers per year. Wisconsin, however, is below the national average, spending \$16.6 million on 5,697 participants for home health services, which is also less than the \$48.5 million spent by neighboring Illinois on its 14,162 participants. Personal care services are also provided to residents in its efforts to provide independent living. In 2010 Wisconsin spent \$155 million on its 14,790 PCS participants (Ng et al., 2014).

1. **Program structure**

The Medicaid HCBS LTSS System in Wisconsin has undergone a significant statewide overhaul since 2008 (Department of Health Services Division of Long Term Care, 2014). This transformation has been enacted with the aim to create more program continuity throughout the state moving away from a system in which all 72 counties were free to implement their own customized programs. The new system moves more of the control to the State, which in turn creates greater access to services for citizens of Wisconsin. Other facets of this transformation include the creation of Aging and Disability Resource Centers. ADRCs operate within the Office of Resource Development under the Division of Long-Term Care which oversees several LTSS options in the state of Wisconsin (Department of Health Services Division of Long Term Care, 2014). The function of ADRCs is to disseminate information and provide counseling in long-term care related decision making for these target groups, effectively facilitating a single entry point system for all potential customers seeking LTSS. Additionally, more managed long term care services and self-directed supports were created. Eligible applicants who contact their local ADRC are offered the choice of selecting a managed long-term care program, such as Family Care, or the self-directed option, IRIS. The ultimate goal of this transformation is to improve service access, provide better choices with regards to goods, supports, and services, create greater future cost effectiveness, and increase quality by focusing on individual outcomes.

ADRCs play a significant role in the Wisconsin LTSS system, disseminating information and representing the single entry point to all services. Certain stipulations are placed upon ADRCs in reference to Family Care. For instance, ADRCs are allowed to contract with other

organizations in the provision of their duties; however, they must maintain complete independence from MCOs to eliminate any conflict of interest when providing counseling and eligibility determinations (APS Healthcare Inc., 2013). The duties of an ADRC are varied. In addition to other services, ADRCs provide information related to all of the disabilities serviced through the centers, referrals to needed services, meet any unmet advocacy needs, long-term care options counseling, counseling from a benefits specialist and choice counseling with respect to enrollment to an MCO and the level of involvement the individual would like to take in their own care management (APS Healthcare Inc., 2013). Eligibility determinations may take place through the ADRC from the performance of functional screening and financial eligibility and cost sharing screening.

2. **Community Integration Program II and Community Options Program Waiver**

Upon demands from Wisconsin's elderly population for improved services in the late 1970s, the state eventually enacted two less controversial reforms by placing a moratorium on nursing home construction and the creation of the Community Options Program (Sparer, 2004). The Community Options Program was first implemented as a state funded demonstration program exclusive to eight counties, but was then converted to a Medicaid Waiver Program applicable to 72 counties. At its conception, COP was thought to be innovative due to the ability of case managers to authorize funds for any necessary service to assist the customer, rather than simply selecting services from a list.

3. **Include, Respect, I self-direct program**

IRIS is a home and community based long term support program in Wisconsin that was established in 2008. Oversight of this program is provided by the Division of Long-Term Care under the Wisconsin Department of Health Services and is authorized through the Centers for Medicaid and Medicare Services (Department of Health Services Division of Long Term Care, 2014). While, DHS is the primary agency responsible for the proper functioning of the program, DHS contracts with three other agencies to assist the participants with successfully achieving their individual outcomes: Aging and Disability Resource Centers, IRIS Consulting Agencies, IRIS Self-directed Personal Care Agencies, and IRIS Fiscal Employer Agents. However, all policy related decisions are directed to DHS, who are responsible for ensuring that all CMS assurance requirements are being satisfied by the program consistent with its approved HCBS waiver application. Any other service providers that are to be utilized must first have Medicaid Provider Agreements in place before any payments can be processed to these providers.

The role of ADRCs is to provide individuals with information facilitating informed decisions about long term care. Specifically, ADRCs perform the following functions: information and assistance, benefit counseling, long-term care options counseling, enrollment/disenrollment counseling, and access to funding for long-term care (Department of Health Services Division of Long Term Care, 2014). IRIS Consultant Agencies (ICAs) provide participants with various services integral to their ability to access the IRIS program. These services are related to enrollment and eligibility such as initial program orientation and skills training familiarizing the participant with the necessary tasks of the program, conducting initial

and recurring functional screens to maintain eligibility, and reviewing budget and expenditure reports with the participant. ICAs also are responsible for managing and assisting the participant with the selection of an IRIS consultant. A participant's IRIS consultant is his or her primary contact responsible for assisting with matters relating to the implementation of the service plan, locating informal and formal service providers, requesting additional funding for exceptional needs, and quality assurance. For participants who are eligible and obtain personal care services through IRIS, the Self-Directed Personal Care Agency (SDPC) may be utilized. Participants are able to receive personal care services through either a certified Medicaid personal care agency or the SDPC. If the participant elects the SDPC option, clinical assessments are provided by agency nurses and the necessary authorizations are obtained for the participant enabling him or her to employ workers. Finally, Fiscal Employer Agents (FEA) acts as an intermediary with regards to payments from the participant to his or her selected providers. The FEA perform essential tasks conducting criminal and caregiver background checks, approving providers or vendors and processing timesheets and payments, securing workers compensation and employee benefit coverage, and presenting participants' workers payments according to the participants' preferred method.

IRIS is made available exclusively to residents of Wisconsin who are eligible for Medicaid and public LTSS, and who reside in counties offering the Family Care program. Since November 2009, IRIS participants have had the option of selecting to receive services under Section 1915⁽ⁱ⁾ of the Social Security Act or from an agency through Wisconsin's Medicaid ForwardHealth card. The program name IRIS is an acronym which stands for Include, Respect, I Self-direct, highlighting the intended goals of this service (Department of Health Services

Division of Long Term Care, 2014). The defining characteristic of this program is that it is a self-directed care program.

4. **Family Care**

Wisconsin's Family Care Program was made possible by the political environment of the 1990's within the state that consisted of a healthy economy, a knowledgeable and professional legislature, and the ambitious leadership of Governor Tommy Thompson (Sparer, 2004). During this time a consensus had developed that Wisconsin's LTSS system was in need of great reform. The answer to this call for action was named "Family Care," and was authorized in 1998 to meet the needs of Wisconsin residents with physical disabilities, intellectual/developmental disabilities, and frail elders (APS Healthcare Inc., 2013). The aim of the program was to improve participants' choices, access to services, social and health outcomes and create cost efficiency. As of July 1st, 2013, the program was available in 57 Wisconsin counties.

Family Care has two primary structural components from which it functions: ADRCs and Managed Care Organizations (also known as Care Management Organizations, henceforth referred to as MCOs). ADRCs provide the public with information regarding beneficial resources available to them, whereas Managed Care Organizations deliver program services to enrollees in a manner tailored to the individual's needs and preferences (APS Healthcare Inc., 2013). MCOs are responsible for maintaining and assuring access to services for eligible participants. This assurance is orchestrated through the development of a comprehensive network of contracts with service providers or through provision from the organization's own employees. MCOs have access to services through Medicaid, HCBS waivers and the Community Options

Program. In exchange for these services, MCOs receive a monthly payment for each participant that is served.

5. **Illinois' Home Services Program**

Where Wisconsin provides LTSS through a varied array of programs, Illinois has one primary offering to its citizens for the purposes of providing HCBS. While Illinois has multiple waivers based upon type of disability, only one directs funds specifically to adults with physical disabilities, the Home Services Program (HSP) (Illinois Department of Human Services, 2009). This program is overseen by the Illinois Department of Public Aid; however its day to day operations are overseen by the Department of Human Services (Joint Committee on Administrative Rules, 2014).

The HSP grants the customer the right of choice in various aspects of his or her service provision under the program. Essentially, this right allows the customer to choose institutional or home based care. While, the customer may select either institutional or home based care, the exact program from which the customer will receive these services is selected by DHS on the basis of appropriateness (Joint Committee on Administrative Rules, 2014). Furthermore, the customer is free from any pressures in the selection of his or her living arrangements, though these selections may impact the level of services available to the customer. The customer is also able to select the particular service provider that will be associated with carrying out any aspect of a customer's case plan, insofar as the service provider meets the established standards.

Both the personal assistant and the customer are also required to sign an employment agreement that binds each of them to certain obligations such as the submission of all necessary documents and that makes each party aware of one another's rights. Various other documents

must be completed and submitted including a PA standards document and, potentially, an I-9 Immigration form (Joint Committee on Administrative Rules, 2014). A personal assistant evaluation must be completed by the customer approving the personal assistant for continued employment. Finally, the personal assistant is required to submit to a background check from the Illinois State Police if requested by the customer. The background check is a free service made available to customers should they elect to utilize it.

The HSP reimburses personal assistants at an hourly rate set by law. This rate is never lower than the current federal minimum wage (Joint Committee on Administrative Rules, 2014). Payments are received twice each month. Each payment reflects services rendered and hours accumulated for that particular payment period. The first payment accounts for hours accumulated from the 1st to the 15th of the month, and the second payment accounts for the remaining days of the month (Joint Committee on Administrative Rules, 2014). Payments are not authorized for greater than 16 hours-worth of services rendered within a 24 hour period, although exceptions apply in emergency situations.

C. **Eligibility**

1. **Community Integration Program II and Community Options Program Waiver**

The Medicaid waivers manual pertains to nine of the Wisconsin Medicaid waiver programs. While, the Children's Long Term Support Waivers serves individuals with physical disabilities under the age of 22, only the Community Integration Waiver II and the Community Options Program Waiver provide home and community based care services exclusively for adults with physical disabilities (Wisconsin Department of Health Services, 2010). The CIP II

and COP-W programs serve both the frail elderly and physically disabled adult populations. Individuals who are deemed to be frail elderly are those who are age 65 and above who's daily functioning is expected to be impaired indefinitely or for the foreseeable future as a result of illness or disability (Wisconsin Department of Health Services, 2010). Adults over the age of 18 with physical disabilities may also be served through these programs. Individuals in these programs are deemed to be physically disabled if at least one of their major life activities is impaired as a result of injury, disease, or congenital disorder. Major life activity is defined through the following list: self-care, performance of manual tasks unrelated to gainful employment, walking, receptive and expressive language, breathing, working, participating in educational programs, mobility, other than walking, and capacity for independent living (Wisconsin Department of Health Services, 2010).

Eligibility is determined based on the following requirement areas: level of care, service need, financial, non-financial, target group criteria, Wisconsin residency and residency setting. Many of these requirements seem self-explanatory in nature while others do not. The level of care necessary for admission into either the CIP II or COP-W programs essentially refers to the level of care deemed necessary for admission into a skilled nursing facility or intermediate care facility (Wisconsin Department of Health Services, 2010). This means that the individual requires assistance with activities of daily living, instrumental activities of daily living or any other need that may be identified through one's functional screen. As for financial eligibility, generally speaking, applicants must have no more than \$2,000 in countable assets. Living arrangements that negate program eligibility include hospitals, nursing homes, Intermediate Care Facilities for the Mentally Retarded (ICF-MR) including any of the state centers, institutions for

mental disease, and jails, prisons or other correctional facilities. Regarding residency, it should also be noted that program participants' funding and services are ensured even in the event of a move or relocation across county lines. This means that a relocation requires the participant's receiving county to adopt the previously agreed upon funding of the sending county.

2. **Include, Respect, I Self-Direct**

There are eight eligibility requirements that must be satisfied for an individual to be a participant in the IRIS program. Eligibility requirements for this program include the following stipulations: 18 years of age, Wisconsin residency, a member of an eligible target group, require a nursing home or Intermediate Care Facility for people with intellectual or developmental disabilities (ICF-IDD) level of care, live in an accepted setting, and have a need for LTSS (Department of Health Services Division of Long Term Care, 2014). From a functional standpoint, applicants must be a member of an eligible target population and require a level of care that would warrant admission into a nursing home or an ICF-IDD, and it must be suspected that he or she will require this level of care for more than 12 months. Eligible target populations include adults with developmental disabilities, physical disabilities, and frail elders. Functional eligibility is determined through a face to face meeting with a qualified screener from the ADRC performs the LTC functional screen. People with physical disabilities must have a physical condition that significantly impairs one major life activity.

In addition to the aforementioned requirements, applicants must also satisfy the financial and non-financial criteria. The financial eligibility requirement stipulates that participants in this program may have no more than \$2,000 in assets. Exemptions include the participant's home, vehicle, and certain burial or funeral trusts (Department of Health Services Division of Long

Term Care, 2014). There are various aspects to the non-financial eligibility criteria. In addition to state residency, the participant or potential participant in question must live in a county or region of the state where managed LTC programs are operating. You may not participate in IRIS if you reside in a county or region that has yet to transition under Wisconsin's state LTC reform initiative. Those with physical disabilities and the frail elderly may be eligible for IRIS if they live in the following settings: private residence, rooming or boarding house, certified Adult Family Home, licensed Adult Family Home, and a certified RCAC. Eligibility will not be lost if a participant is institutionalized on a short-term basis, however services will be suspended for the duration of the institutionalization period. If the institutionalization becomes a long-term stay, eligibility for the IRIS program will be lost.

3. **Family Care**

In order to be eligible for the family care program, enrollees must meet certain criteria involving the person's age, residency, target group status, functional capacity, financial status, and non-financial conditions. Other criteria may apply, such as depending upon the financial determination cost sharing requirements may come into effect, and if the individual is eligible for medical assistance he or she is required to accept (APS Healthcare Inc., 2013). Accepted applicants of the Family Care Program are Wisconsin residents of counties where Family Care is available and who are of at least 18 years of age. These individuals have physical or developmental disabilities or are frail elders. Eligibility is redetermined annually.

Enrollees of this program must be determined through the functional screening process to possess certain levels of functional capacity. More specifically, to be eligible the applicant must have a long-term or irreversible condition, and unless being transferred to the Family Care

Program from specific alternative care programs, the individual's functional capacity must be determined to be either at the comprehensive or intermediate levels (APS Healthcare Inc., 2013).

4. **Illinois' Home Services Program**

There are several requirements that must be met for one to be deemed eligible for HSP. As for financial eligibility criteria, applicants above the age of 18 may have no more than \$10,000 in assets (Joint Committee on Administrative Rules, 2014). However, certain assets are exempt from those included in the asset limitation requirement. The same eligibility requirement stands for applicants who are married as well, in that their portion of the couples' total assets may not exceed \$10,000. There are also non-financial eligibility requirements that must be met for admittance into the HSP. The first requirement is that the applicant must be a legal citizen of the United States (Joint Committee on Administrative Rules, 2014). The next requirement involves an individual's Medicaid status. An applicant must show within 60 days after his or her application to the HSP that the individual has either applied, been found eligible, or be a recipient of Medicaid benefits (Joint Committee on Administrative Rules, 2014). In addition, applicants of HSP must also be residents of the state of Illinois to maintain eligibility. Applicants must be under the age of 60 at the time of their application to the program, and must also have a severe disability that is expected to be present for at least 12 months (Joint Committee on Administrative Rules, 2014). Finally, a Determination of Need assessment must be provided to the applicant on which the applicant must receive a combined score of at least 15 on Part A and the Mini-Mental Status Examination with a total score of at least 29 (Joint Committee on Administrative Rules, 2014). This individual must also not require services which exceed those

allotted based upon the score received on the Determination of Need Assessment. All of these requirements must be met for an individual to be determined eligible for the HSP.

The Determination of Need (otherwise known as DON) is responsible for the nonfinancial aspect of one's eligibility clarification; it is also used in the pre-screening process for individuals without mental impairments who desire to be institutionalized (Joint Committee on Administrative Rules, 2014). The DON is made up of three separate assessments. The first assessment is the Mini-Mental Status Examination, which is used to test the customer's cognitive function. This test is optional, and performed only if the HSP staff member's personal judgment identifies "cognitive problems" through interaction with the customer. Regardless of whether or not the Mini-Mental Status Examination is performed, the next section of the assessment is Part A. This test assesses the customer's personal ability to carry out and complete Activities of Daily Living. Specifically, the HSP identifies the following ADLs: eating, bathing, grooming, dressing, transferring, incontinence care, preparing meals, being alone, telephoning, managing money, routine health care tasks, specialized health care tasks, necessary travel outside the home, laundry, and housework. The participant's ability to complete each ADL is graded on a scale of zero to three, with zero indicating the participant can perform all essential components of the activity and three indicating the participant not perform any of the essential components. The final section of the DON is Part B, which assesses the care the customer receives through informal support structures such as family, friends and the community. Incorporating informal supports the participants is graded on a scale of zero to three, with zero indicating the ADL is already completed by family or other resources, one indicating the participant's need for assistance with an ADL is fulfilled at least 50% of the time, two indicating the participant's need

I for assistance with an ADL is fulfilled less than 50% of the time, and three indicating the participant's need for assistance in completing an ADL is fulfilled less than 10% of the time.

Based upon these three tests, a score is developed that is used to identify a corresponding Service Cost Maximum, which is the maximum amount of funding allowed for that participant each month for all expenditures within the HSP (Joint Committee on Administrative Rules, 2014). A chart is used to determine each participant's SCM. The chart breaks down the potential DON scores into seven scoring ranges with corresponding funding brackets, with a minimum score being 29 and the maximum possible score being 100. Respite services are also available through this program based upon scores indicating total need from both the Mini Mental Status Examination and Part A of the DON. SCMs can be exceeded for special circumstances lasting no more than three months, if the participant's average monthly service cost does not exceed the SCM (Joint Committee on Administrative Rules, 2014). In addition, individuals requiring a level of care that cannot be met under the typical SCMs may be awarded an exceptional care rate. The exceptional care rate is determined by taking into account the exceptional care rate provided by the nearest approved nursing facility to the participant's home.

D. **Services Offered**

1. **Community Integration Program II and Community Options Program Waiver**

Aside from personal care services, CIP II and COP-W provided a wide range of supports. Specifically, these two programs provide the following services to eligible participants; Adaptive Aids, Adult Day Care, Adult Family Home, Care Management/Support and Service Coordination, Children's Foster Care/Treatment Foster Care-Developmental Disabilities,

Communication Aids, Community Based Residential Facility, Counseling and Therapeutic Services, Daily Living Skills Training, Day Services, Financial Management/Fiscal Intermediary Services, Home-Delivered Meals, Home Modifications, Nursing Services, Personal Emergency Response System, Relocation Related-Housing Start Up, Residential Care Apartment Complex, Respite Care, Specialized Medical and Therapeutic Supplies, Specialized Transportation, Support & Service Coordination/Care Management, Supportive Home Care, Vocational Futures Planning (Wisconsin Department of Health Services, 2010).

Of the aforementioned provisions available under the CIP II and COP-W waiver programs, the most important for our purposes is the Supportive Home Care service. Under this provision, participants benefit from various services, including Personal Services, Household Services, and funding for “live in” care providers. The various duties associated with the Personal Services aspect of this provision include: assistance with ADLs, assistance with adaptive equipment, mobility and communication aids, accompaniment to community activities, assistance with medications, attendant care, supervision and monitoring, observation of the participants’ condition and needs, and assistance with therapy services (Wisconsin Department of Health Services, 2010). As for the requirements of Household Services, care providers assist with household task and home maintenance activities, as well as with packing and general house cleaning. Funding in CIP II and COP-W is also made available for room and board costs of care providers who assist participants on a “live in” basis. The spouse of a participant is restricted from reimbursed care provision (Wisconsin Department of Health Services, 2010). Care providers are also reimbursed for any transportation costs they may incur.

2. **Family Care**

To receive services through the Family Care Program individuals must enroll with an MCO. Services provided will be consistent with the individual's service plan, which is tailored to his or her specific needs and values. Services typically included with these programs are: adaptive aids, adult day care, assessment and case planning, case management, communication aids and interpreter services, counseling and therapeutic resources, daily living skills training, day services and treatment, home health services, home modification, home delivered and congregate meal services, nursing services, nursing home services including care in an intermediate care facility for the mentally retarded or in an institution for mental diseases, personal care services, personal emergency system services, prevocational services, protective payment and guardianship services, residential services, respite care, durable medical equipment and specialized medical supplies, outpatient speech, physical and occupational therapy, supported employment, supportive home care, transportation services, mental health and alcohol or other drug abuse services and community support program services (APS Healthcare Inc., 2013).

3. **Illinois' Home Services Program**

Once eligibility has been determined, each HSP customer is provided with a Service Plan. The Service Plan outlines what the customer is to be allotted under the HSP and the specific guidelines for its allotment. The service plan includes: services to be provided, the tasks associated with those services, the frequency those tasks are to be provided, the number of hours the customer is approved for in association with each task, payment rates, and if applicable, the customer's back up plan in the event that a Personal Assistant is not available (Joint Committee

on Administrative Rules, 2014). The stipulations of a Service Plan are to outline a plan of care that will be necessary to meet an unmet care need of the customer and that the services used to meet that need are safe and adequate, cost effective and the most economical method available to meet that need. The services outlined in the Service Plan are to be provided to the customer unless they have left their home due to hospitalization, entrance into a skilled nursing or intermediate care facility, no longer residing in his or her home, or if the individual has left the State of Illinois. The services can be withheld in the aforementioned cases unless they conflict with certain exceptions. Services can be maintained when a customer is at his or her place of work, if the absence from home is for a predetermined period, and if the customer is hospitalized and has a DON score of 75 or higher.

The services offered under HSP include: personal assistant services; adult day care services; homemaker services; maintenance home health services; home delivered meals; electronic home response services; assistive equipment; environmental modification; respite services; day habilitation services; pre-vocational services; supported employment services; and behavioral services (Joint Committee on Administrative Rules, 2014). A requirement of the Personal Assistant Service Provision is that the customer enters into an Employment Agreement with the personal assistant.

For the purposes of this inquiry, the most salient of the services offered is the Personal Assistant (PA) provision. Personal Assistants receiving payments for participating in this program must satisfy certain requirements including: verification of a Social Security Number, two references, the ability to communicate with the customer, the ability to follow directions, experience or training in the required tasks, knowledge of precautionary procedures for the

control of any infectious diseases, if applicable to the customer (Joint Committee on Administrative Rules, 2014). DHS also identifies an age requirement for Personal Assistants. Personal Assistants who are age 18 or older are permitted, however Personal Assistants between the ages of 14 and 16 must have an employment certificate and be supervised by an adult of at least 21 years of age who is legally responsible for the customer. Personal Assistants age 16 or older are only permitted to work during non-school hours.

Personal Assistants are authorized to assist with household tasks, shopping and personal care. They may also be permitted to assist with incidental health care tasks if requested by the customer insofar as these tasks do not require independent judgment (Joint Committee on Administrative Rules, 2014). In addition Personal Assistants are authorized to monitor the customer ensuring his or her health and safety.

E. **Managed Care**

As a condition of being a certified MCO, these organizations must have case management capability as well as an adequate availability of providers. MCOs must consider any enrollee request for services from providers that do not have existing agreements for service provision (APS Healthcare Inc., 2013). Each enrollee is assigned a case management team by his or her MCO consisting of at least a social services coordinator and a registered nurse. The enrollee is provided the opportunity by the MCO to manage his or her own service funding. The level of involvement of the case management team and the degree of freedom afforded the enrollee in the case management duties is negotiated between the two parties. The case management team must at the least be responsible for the initial assessment, budget monitoring, service utilization monitoring, and health and safety monitoring.

An assessment of the enrollee is provided, including a face to face interview, to the degree necessary to determine an individual budget amount and identify any health and safety issues (APS Healthcare Inc., 2013). An initial service plan is provided within five days of enrollment. An individualized service plan is issued within 60 days of enrollment that is developed through partnership with the MCO and the enrollee, identifying the enrollee's long-term care disparities and personal strengths, long-term care outcomes assisting the enrollee to their desired level of autonomy, while maintaining cost-efficiency.

F. **Self-Determination/Self-Direction**

1. **Community Integration Program II and Community Options Program Waiver**

Participants are not eligible for Supportive Home Care through CIP II and COP-W if they reside in a residential care complex. Self-direction of care services is available to participants if they choose, but the waiver agency must first assess the participant's ability to self-direct before this ability is authorized. Even then, the waiver agency provides support to the participant in self-directing their service. Supportive Home Care requires that county and provider agencies have back up services available to participants in the event that a designated care provider is not available (Wisconsin Department of Health Services, 2010). Once eligibility has been established and assessments have been provided, participants can begin receiving services through CIP II or COP-W. For these and other waivers in Wisconsin, the State Medicaid Agency has direct agreements with local service providers to carry out the responsibilities of the actual service provision. It is the responsibility of the county waiver agency to assess service providers approximately every four years to ensure that service delivery meets all of the

corresponding standards (Wisconsin Department of Health Services, 2010). Upon admission to the program, during review of their individual service plan, and at any point that it is requested, program participants have the right to and are required to be informed of his/her choices of qualified service providers. All service providers are required to register to be included in the Medicaid Waiver Provider Registry, which is available to all agencies and participants.

All individuals who “have regular, direct contact with waiver participants” or provide services outlined in an Individual Service Plan are required to complete a caregiver and criminal background check (Wisconsin Department of Health Services, 2010). Consequently, service providers are not allowed to employ, contract with, or accept volunteer service from anyone convicted of child abuse, neglect, maltreatment or a felony involving harm to a participant of any other waiver or health and human services program. Not only are restrictions placed upon providers from hiring such individuals, individuals who fail these background checks are also barred from receiving any COP or waiver funds. This means that even under a self-directed services plan participants themselves would be restricted from hiring these individuals. However, any potential employee whose background check does not reveal a “serious or substantially related crime.”

2. **Include, Respect, I Self-Direct**

Being that IRIS is a program that emphasizes the philosophy of self-direction, participants are able to personally, or with the help of a designated party or legal representative, make informed decisions about: what goods, supports, and services they require to meet their identified outcomes; the ability to use their allotted budget responsibly and cost effectively; the level of assistance they require to make these decisions; and the amount, location, and provider

of their services. It is believed that this freedom allows participants to lead more meaningful lives in their communities. Furthermore, it is believed that by creating this program with self-direction in mind, the participants are empowered, gaining freedom over the way they live their lives, authority over their budgets, recognition for their ability to contribute, the respect of being entrusted to use public dollars wisely, and confirmation of their roles as self-advocates.

Participants work to implement their personal plans with the assistance of their IRIS Consultant Agency and their IRIS Fiscal Employer Agent. Participants do not receive funds to pay for services directly; rather payments are made through the FEA and the Third Party Claims Administrator (Department of Health Services Division of Long Term Care, 2014). In terms of employing individuals to carry out desired services, participants can either elect to carry out this function on their own as a common law employer, or they can choose to become a co-employer with an agency. As a common law employer participants have all of the responsibilities typical of any organization such as hiring, training, scheduling, directing, and reviewing and approving any employment related documents. As a co-employer, the participant shares these responsibilities with an agency which is actually the employer of record.

3. **Illinois' Home Services Program**

DHS does not, however, intervene into the relationships between its customers and their personal assistants. The customer serves as the employer of the PA taking responsibility for all matters relating to the hiring, training, directing and termination of the employee. This places a strong emphasis on the customer's self-direction except in cases where the individual is unable to perform the required duties, in which case a family member or

guardian can assume the previously mentioned responsibilities (Joint Committee on Administrative Rules, 2014).

G. **Summary**

In this chapter, two state Medicaid HCBS programs were described and analyzed for the presence and promise of liberalism. The liberty of disabled people and those who will be disabled in the future is supported through the actions of the State. Infringements on individual liberties represented by the generation of revenue from the masses via taxation (i.e., less opportunity to spend individual money as desired) enable the State to act. These infringements are balanced against the need for justice in the form of a reduction of social and economic inequality through increased positive liberty for all. In this way, each of these service offerings represent efforts toward the creation of positive liberty for participants and society at large, albeit to different degrees. This can be said, being that these services are offered through the creation of certain restrictions, namely the taxation requirements placed on citizens for the funding of these programs, in an effort to create a greater sense of liberty that would not be available without intervention. The services offered to potential applicants within each state creates opportunities for the empowerment of the disability community. In Illinois and Wisconsin, individuals with disabilities have opportunities to have their unmet needs accommodated through state funding aimed at providing, among other provisions, the aid of nonprofessional care providers. This does not mean that each of these systems do not differ with regard to their ability to reflect liberal goals and principles. A liberal framework highlights the need for each system to be judged on and focus its efforts towards championing personal autonomy in their program participants. Based upon this particular motivation, opportunities for improvement within each system can be

elucidated. While Illinois' offering of its service with less oversight bodes well for the preservation of liberty, particularly of the negative variety, the lack of financial investment presents a significant loss in terms of its opportunity to add to its offerings of positive liberty. That being said, Wisconsin's heightened investment in its own assortment of services creates accommodations for its citizens with disabilities to access positive liberty to a degree that is not available in Illinois. Each of these insights pertaining to the liberal principles of positive and negative liberty provide a greater understanding of the effectiveness of these services in terms of disability policy, while also identifying implications of recommendations for future program implementations. Maximizing positive and negative forms of liberty serves the autonomy of citizens of liberal governments. This fundamental characteristic of liberal citizens is the stated goal of the IL paradigm and community living policy. In the next chapter, I will address opportunities to expand upon the stated goals of liberalism in reforms to current policies.

VI. THE PROMISE OF LIBERALISM FOR STATE MEDICAID HOME AND COMMUNITY-BASED SERVICES PROGRAMS

LTSS is often confused with a related concept commonly associated with impairment, Long term care (LTC), which addresses the needs of the individual through a range of supportive, rehabilitative, palliative or nursing services (Rosenfeld & Russell, 2012). LTC services are often provided in an institutional-based setting, but can also be provided in-home in the form of home health care or retirement community that provide home-health-skilled nursing services. Therefore, where LTC prioritizes maintaining the health and vitality of the patient by providing professionalized and skilled care, LTSS is concerned first and foremost with supporting the independence of the consumer

The position of the IL movement supports the argument that in many cases the tactics of the healthcare field contradict and are ill-suited to the unique circumstances of people with long-term disabilities who are often informed decision makers with respect to their health and bodies, as a result of their previous experiences with their own disability (White et al., 2010). Healthcare often emphasizes the scientific development of cures or treatments for identified pathologies, disregarding those disabled individuals for which such remedies do not exist (Silverstein, 2010). This increasingly antiquated approach is premised upon certain preconceived notions regarding disability in popular western society, which largely revolved around the assumption that these individuals are incapable of experiencing life to its fullest extent. Undergraduate nursing education in the US still relies heavily upon this past approach to healthcare and its views towards people with disabilities (Rosenfeld & Russell, 2012). As a result, healthcare policy requires a new approach to disability, one that recognizes disability as a normal part of the

human experience. The motivations of the IL movement coincide with the benefits of LTSS policies, which aim to ensure one's disability does not detract from his or her opportunities for social inclusion.

Liberal theory provides the best possible framework for the implementation of LTSS in a manner that best embodies the highest ambitions of the IL movement. This is due to its balanced approach to policy that is capable of providing public interventions that provide opportunities and minimize inequalities with respect to groups like the disabled, while also preserving citizens' liberties, or otherwise referred to as maintaining one's ability to self-direct and be fully autonomous. These benefits for people with disabilities relying upon LTSS are seen in the liberal principle of a dedication to a pluralist society, and the IL paradigm's promotion of self-direction.

A. **Pluralism**

Within liberal thought there is some debate over the nature of the personal autonomy guaranteed through liberalism, that based upon *reason* and that aimed at producing the *political management of diversity* (Tate, 2013). Each form finds its origin in historically notable eras, the former in the Enlightenment and the latter in the Reformation. Being liberal theories, each of these two forms assert the primacy of liberty or freedom, however, they both accomplish this in vastly different ways. A representation of each form in terms of the particular psychological theory that is necessary to understand the interpretation of mankind implied by each of these opposing definitions is illuminating in regards to comprehending their theoretical differences. The first form purports a rationalist or moral theory of psychology, while the second employs a more romantic view of the psyche (Stolzenberg, 2009). Popularized by Christian and classical liberal thought, the former utilizes reason to equate virtue with freedom and following one's

passions to slavery, ultimately eventually leading to the liberal belief in the need to regulate certain behaviors. A romantic theory of psychology, on the other hand, allows for the opportunity for individuals to be guided by forces other than reason, including their own irrational impulses and desires, experiencing freedom through self-expression. This theory describes a psyche that has been the impetus for significant social transformations over the past two centuries including: women's liberation, sexual liberation, reproductive freedom and gay rights. This version of liberal autonomy associated with the management of a diverse and wide range of equally recognized understandings of what is valuable or moral in life is recognized as the true form of liberalism (Stolzenberg, 2009; Tate, 2013). Conventionally put, this means that liberalism is committed to a *pluralistic conception of the good* and cannot simply dictate or condone any specific normative doctrine over another regardless of its basis in reason (Francis & Silvers, 2007). This aversion to dependency and the preservation of the wish to pursue one's own depiction of a desirable life exhibited through a pluralistic conception of autonomy are the driving force seen in the advocacy of the IL paradigm for a self-directed care model (Fleischer & Zames, 2011).

B. **Self-Direction**

One of the most salient methods by which people with disabilities shed dependency is through the provision of home support services (often referred to as personal assistance services or PAS). These home or community based supports are largely provided by non-medical personnel for the specific purpose of the completion of Activities of Daily Living, and ultimately the achievement of social, economic and political inclusion. Comparable in many respects to a form of assistive technology, this fundamental service creates access to full citizenship and

participation in the community (Krogh & Johnson, 2006). PAS provides people with disabilities opportunities otherwise exclusively available to able bodied individuals including employment and its associated benefits (Prideaux et al., 2009). Workplace PAS is critical to providing people with disabilities the opportunity for employment and can be defined as a reasonable accommodation required by the ADA (Dowler et al., 2011).

Historically, two distinct models of PAS have developed: the homecare agency and self-directed models (NCD, 2013). The agency model structures the service delivery format such that Medicaid funding is utilized to employ professionals such as nurses, social workers and paraprofessional aides who work to train and supervise service providers according to agency standards, whereas the self-directed model allows consumers or program participants adopts the majority of the responsibility for all recruiting, hiring, training, supervising and replacing of service providers (Benjamin et al., 2000). Medicaid funding can be channeled through the participant in the self-directed care model, but are often paid to providers directly. Essentially, the self-directed model allows eligible participants to interpret their own needs and wishes, maintaining significant authority over service design, including selecting the necessary resources and staffing, assigning provider roles and ensuring service and support efficiency to meet those needs (NCD, 2013). In addition to employer authority over managerial activities, additional budgetary authority can allow participants to purchase goods and services providing even greater personal freedom and self-reliance. It also is accessible to individuals with a variety of impairments through the option to designate a representative to direct the care (Shen et al., 2008). Demand is stronger amongst certain populations over others. The CCDE found some characteristics to be associated with the preference for a cash option such as the severely

disabled when compared to those with mild or moderate disabilities, and ages between thirty and sixty with those in their twenties being least likely to prefer to take on these responsibilities (Mahoney et al., 2004).

Rule changes to the Social Security Act have affected service planning for individuals enrolled in programs under sections 1915^(c) and 1915⁽ⁱ⁾ such that this process must be directed by the consumer, reflecting his or her individualized goals and preferences and result in a plan that aides in the achieving of these outcomes (Medicaid Program, 2014). This does not, however, mandate the full implementation of a self-directed care model as described above. To this point, the US has experimented with public implementation of such a program through The Cash and Counseling Demonstration and Evaluation. In short, this program aimed to test offering elders and working age adults with physical disabilities greater consumer direction through cash allowances equivalent to that spent on agency-based services (Mahoney et al., 2006). Four states were intended to be included in the program, but only Arkansas, New Jersey and New York ultimately participated.

Self-direction has been associated with improved outcomes in terms of personal care and overall well-being, demonstrating a decreased incidence of health problems and fewer unmet needs, and at worst comparable results to alternative models (Benjamin et al., 2000). Combined with higher satisfaction and overall quality of life, all while potentially resulting in more efficient work being carried out, the benefits of such a service delivery method are undeniable (Carlson et al., 2007). It also presents an opportunity for people with disabilities to shed the stigma that accompanies the welfare dependency qualification within US Medicaid policies and instead be likened to a small business owner (Prideaux et al., 2009). Not only does being perceived as self-

directing aid the individual with a disability, it requires the fostering of the development of certain characteristics, which would constitute employment in other circumstances. While the employment of care providers through state provided funding does not have a direct equivalency to small business ownership, it differs vastly from the volunteerism it would more often be compared. The foundational role home support plays in the lives of people with disabilities makes it a necessary element of any meaningful policy from a disability rights standpoint.

C. **Insights for Future Policy**

Current PAS delivery is plagued by many complications that inhibit optimal outcomes. Standards pertaining to LTC workers are generally minimal. This lax state is even more so in terms of homecare providers, with binding training and supervision requirements for non-medical homecare personnel and aides only established in 29 states. Furthermore, only half (15) of these states have supervision requirements within the first 90 days (Kelly et al., 2011). Overall, PAS programs experience problems largely derived from limited interest by potential personal assistants, attributable to low wages, lack of benefits and sporadic hours in addition to the training responsibilities of consumers who are often inexperienced with employee training methodologies (Dowler et al., 2011). Some argue that the legitimization of the field through an increased standardization of practices would resolve many PAS issues. By identifying the core competencies of homecare positions, benefits clients, employers and workers by enhancing the ability to assess worker effectiveness and creating opportunities to access career advancement (Kelly et al., 2011). Specifically, basic core competences should include proficiency in relevant agency policies and client rights, ADL and IADL assistance, environmental maintenance, misconduct reporting and communication, while advance skills should include equipment

competency, emergency and accident awareness, experience with key community providers, a nuanced understanding of client's needs, behavioral skills and cultural awareness (Kelly et al., 2011). Regardless of these complicating factors, PAS programs are the foundation of community living for people with a wide variety of disabilities that desire to remain in the community (Fleischer & Zames, 2011). Many HCBS programs, particularly those offering PAS, suffer from complications related to the staffing of care providers. One being that there are minimal standards in terms of homecare providers (Kelly et al., 2011). Overall, these programs experience limited interest from potential personal assistants due to low wages, lack of benefits and sporadic hours in addition to the training responsibilities of consumers who are often inexperienced with employee training methodologies (Dowler et al., 2011). Many of these complications could be improved through legitimization of the personal assistant field through increased standardization of practices and the identification of the core competencies of homecare worker positions, clients, employers and workers. This would potentially enhance assessment of worker effectiveness, creating additional opportunities to access career advancement. Some have identified basic core competences such as: proficiency in relevant agency policies and client rights, ADL and IADL assistance, environmental maintenance, misconduct reporting and communication, while advance skills should include equipment competency, emergency and accident awareness, experience with key community providers, a nuanced understanding of client's needs, behavioral skills and cultural awareness (Kelly et al., 2011). Further investigation into additional competencies could benefit this endeavor.

Another avenue for the remedy of workforce complications within HCBS involves opening the labor force to added groups. Currently, undergraduate nursing education largely

reflects a medical model of understanding issues related to people with disabilities. This education does not inform the students about home care opportunities, nor does it equip them with the necessary skills to work in this particular setting (Rosenfeld & Russell, 2012). Through the incorporation of elements of the social model to these educational offerings, the students would potentially provide HCBS programs with skilled care providers. Similarly, care providers within PAS programs are provided with limited wage compensation, presenting a significant deterrent to potential employment (Dowler et al., 2011). While facility-based care staff wages continue to increase, homecare aides receive a fraction of this compensation (Issar et al., 2012). Through minimizing this wage-gap, unskilled and skilled laborers would be more apt to consider these acceptable positions of employment. Regardless of these complicating factors, PAS programs are the foundation of community living for people with a wide variety of disabilities that desire to remain in the community (Fleischer & Zames, 2011).

Satisfaction measurements vary widely depending on care setting. When speaking of institutional care, there are many standards and regulations put into place to ensure patient satisfaction. However, the care provided within an institutional setting vastly differs from that made possible by HCBS, which in turn, transforms the way quality is perceived. Satisfaction in an institutional setting is attained through licensure and training requirements, yet this manner of quality assurance sidesteps matters of satisfaction. One way organizations and agencies have attempted to assure that their programs are “person centered” is by creating opportunities for participants to maintain greater control over the care that they receive (Folkemer & Coleman, 2006). We see this in many of the programs discussed here. Illinois’ home services program allows individuals total control over matters related to their care providers. The same can be said

with respect to the IRIS program, as it also demonstrates a consumer directed form of PAS. Despite this effort toward “person centered” care, the typical modes of satisfaction assurance, even when dealing with homecare, are centered on “structure and process.” Agencies and care providers work to abide by state and federal regulations regarding such aspects of quality as agency licenses, number of personal care worker training hours, and agency performance (Folkemer & Coleman, 2006). These types of quality measures do not address the participant’s satisfaction, his or her opinions concerning the effectiveness of the care received, or the ability of the program to improve their quality of life. Wisconsin’s COP has implemented a quality assessment and improvement program, which consists of such elements as between 400 and 500 visits per year to LTSS clients in their homes by a quality assurance coordinator (Folkemer & Coleman, 2006). A focus on a person-centered quality is also found in the Family Care Program. This attention to quality is evidenced by a 2003 report that concluded, “the program has substantially met the goal of increasing choice and access and improving quality through a focus on social outcomes” (Wisconsin Legislative Audit Bureau, 2003, p. 109).

The second observation concerns choice. Weiner provides several suggestions of ways that the LTSS system can be rebalanced in a way that substitutes institutional care with home and community based alternatives (Wiener, & Anderson, 2009). Two of these suggestions are particularly pertinent, the first being that of single point of entry systems. The philosophy behind single-point-of-entry systems is that, whereas, institutional options are more streamlined with the majority of resources being provided by a single source, home and community based options are diversified with services being provided through multiple sources with distinct application processes and eligibility requirements (Wiener & Anderson, 2009). Therefore, it is believed that

by overcoming this initial obstacle and offering information to the public uniformly and without complexity, individuals seeking LTSS will, all things being equal, select the home-and-community-based option in increasingly wider margins (Kane, Priester, & Kane, 2007). This strategy is evident in the Wisconsin model through the ADRCs making it possible for residents to successfully manage their own long-term care needs.

The more widely available and accessible knowledge brought about through ADRCs aids in the navigation of a system with great variety. Through the availability of more low-cost home and community-based options, individuals capable of being served at a lower cost will seek out those alternatives, lowering expenditures and creating more opportunities for individuals to receive their services in the home or community (Wiener & Anderson, 2009). This strategy more closely describes the Wisconsin LTSS system. Wisconsin offers a wide selection of home and community-based Services to meet the needs of their residents. This selection includes distinctive options through a variety of differing service delivery methodologies, including the self-direction capable of participants enrolled in IRIS, managed care in Family Care for those desiring to customize their level of self-direction, and the flexibility of CIP and COP to accommodate the individual needs of wide populations with varying disabilities and unmet needs.

D. **Summary**

The Independent Living Movement articulated the devotion of US citizens to independence and freedom, demonstrating society's obligation in this regard to their peers with disabilities. Community-based services in the form of LTSS represent the primary mechanism through which citizens with disabilities assert their right to express their capacity for autonomy

and society's acceptance of a duty to ensure one another's equitable opportunities, specifically in terms of those available to the disabled being on par with the nondisabled. Liberalism has the tools to provide disabled people access to equitable levels of freedom to that of non-disabled citizens through a balance between promoting progressive policies and an activist government and endorsing restrictions necessary to protect individual freedoms.

Liberal theory accepts this understanding of the importance of human autonomy and the need for its protection. Largely through his articulation of the social contract, John Locke (1694) provides a basis for limited government with robust property rights that concentrates on securing negative liberty. This form of argumentation has come to be synonymous with classical liberalism. Modern liberalism, on the other hand, puts forth a reinterpretation for the purposes of expanding citizen's rights to positive liberty. Rawls argues for this expanded role of government primarily through his second principle of justice, which supports social and economic protection of citizen's rights to equality of opportunity and from unwelcomed inequalities. Thus, liberty in the form of personal autonomy emerges both through negative protections (i.e., freedom to pursue one's version of a good life) in a classical scheme, as well as positive constructions (i.e., services enabling citizens with disabilities to remain independent) endorsed by modern liberals. Personal autonomy is both preserved through one's formal rights characteristic of a pluralistic society and affirmed through substantive rights to opportunity and security. Liberal devotion to personal autonomy demonstrates parity with the motivations of the IL paradigm.

A shared vision of society's respect for individual autonomy represents potential for disability advocates to transform the theoretical promise of liberalism to practical application. Past neglect of the citizenship of people with disabilities within liberal theory, in addition to

other current and historical injustices, can lead one to believe in an incapacity of liberalism to accommodate the aspirations of people with disabilities for society. Despite exclusion of disability from consideration in most major manifestation of liberalism, liberal theory possesses a capacity for logical reinterpretations that extend theoretical support for the equal citizenship of people with disabilities. Similar to the IL paradigm, liberalism prizes personal autonomy as a fundamental human right. Consequently, liberalism has potential to assess disability policy in relation to support of personal autonomy. In this vein, Medicaid HCBS policy systems and programs are particularly appropriate object of inquiry given the influence of these programs on access to community living and employment opportunities for disabled people.

The liberty of disabled people and those who will be disabled in the future is supported through the actions of the State. In this way, service offerings represent efforts toward the creation of positive liberty for participants and society at large, albeit to different degrees. Infringements on individual liberties represented by the generation of revenue through taxation for the funding of these programs (i.e., LTSS) are balanced against the need for justice in the form of a reduction of social and economic inequality through increased positive liberty for all. This calculation is made in an effort to maximize one's sense of liberty that would not be available without intervention. Services offered to participants within each of these states create opportunities for empowerment of the disability community. A liberal framework highlights the need for each system to be judged on and focus its efforts towards championing personal autonomy in their program participants. In Illinois and Wisconsin, citizens with disabilities have opportunities to have unmet needs for the facilitation of their independence accommodated through state funding of, among other provisions, the aid of nonprofessional care providers. Each

of these systems differ in their ability to reflect liberal goals and principles, namely the maximization of autonomy. While Illinois' offering of its service with less oversight bodes well for the preservation of liberty, particularly of the negative variety, the lack of financial investment presents a significant loss in terms of its opportunity to add to its offerings of positive liberty. That being said, Wisconsin's heightened investment in its own assortment of services creates accommodations for its citizens with disabilities to access positive liberty to a degree not available in Illinois. Each of these insights pertaining to the liberal principles of positive and negative liberty provide a greater understanding of the effectiveness of these services in terms of disability policy, while also identifying implications of recommendations for future program implementations.

Maximizing positive and negative forms of liberty serves the autonomy of citizens of liberal governments. This fundamental characteristic of liberal citizens is the stated goal of the IL paradigm and community living policy. Opportunities to expand upon the stated goals of liberalism exist in reforms to current policies. By adhering to principles of liberal theory that had previously overlooked people with disabilities, and reinterpreting them in a logically sound and inclusive manner, the insights highlighted within this essay demonstrate the opportunities that lie ahead through embracing rather than replacing this form of policy making. Given the centrality of LTSS programs in the lives of disabled people who demand meaningful and equitable community integration, the capacity of liberal theory to maximize personal autonomy through both negative and positive means represents its suitability to be used to analyze current programs and create new policies that empower people with disabilities without resorting to paternalistic missteps.

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