

University of New Hampshire

University of New Hampshire Scholars' Repository

Honors Theses and Capstones

Student Scholarship

Spring 2021

Care Ethics, Disability, and Public Policy

Piper Gibson

University of New Hampshire, Durham

Follow this and additional works at: <https://scholars.unh.edu/honors>



Part of the [American Politics Commons](#), [Disability Studies Commons](#), [Ethics and Political Philosophy Commons](#), [Feminist Philosophy Commons](#), and the [Political Theory Commons](#)

Recommended Citation

Gibson, Piper, "Care Ethics, Disability, and Public Policy" (2021). *Honors Theses and Capstones*. 580. <https://scholars.unh.edu/honors/580>

This Senior Honors Thesis is brought to you for free and open access by the Student Scholarship at University of New Hampshire Scholars' Repository. It has been accepted for inclusion in Honors Theses and Capstones by an authorized administrator of University of New Hampshire Scholars' Repository. For more information, please contact nicole.hentz@unh.edu.

Philosophy & Political Science Honors Thesis

Fall 2020-Spring 2021

Care Ethics, Disability, and Public Policy

Written by: Caroline “Piper” Gibson,

University of New Hampshire Undergraduate, Class of 2021

Completed Under the Advisement of:

Prof. Charlotte Witt (Philosophy) & Prof. Tama Andrews (Political Science)

Secondary Thesis Readers:

Prof. Nicholas Smith & Prof. Subrena Smith

Table of Contents

Introduction and Overview	4
1.) A Social Constructionist Model of Disability	6
• Introduction to the Social Constructivist Model of Disability.....	6
• The Impact of Resource Allocation.....	10
• Martha Nussbaum on Disability.....	11
• Iris M. Young on Disability.....	17
• Eva Kittay on Disability.....	21
2.) Care Ethics and Disability	26
• The Origin of Human Dignity.....	26
• Inevitable Dependency.....	28
• Justice that Includes Dependency.....	32
• Connections-Based Equality.....	34
• An Ethic of Care.....	35
• The Role and Needs of Dependency Work.....	38
• Doulia as a Model for Care.....	45
3.) Conceptualizing Political Policies	51
• Background to Wicked Problems.....	51
• Defining Wicked Problems.....	53
• Solutions to Wicked Problems.....	60
• The Issue-Attention Cycle.....	62
4.) Paid Family Leave (PFL)	69
• Introduction to Paid Family Leave.....	69
• The Family Medical Leave Act (FMLA).....	70
• Case Study: Paid Family Leave in Connecticut.....	72
• Benefits to Implementing Paid Family Leave.....	75
• Misconceptions about Paid Family Leave.....	84
• Political Considerations.....	86
• Wicked Problems and Paid Family Leave.....	89
• Recommendation.....	92

5.) The Community Choice Act (CCA)	95
• Introduction to the Community Choice Act.....	95
• <i>Olmstead v. L.C.</i>	96
• Current Implementations of the CCA at a State Level.....	98
• Benefits of the Community Choice Act.....	100
• Political Considerations.....	107
• Constraints and Challenges.....	109
• The Issue-Attention Cycle and the CCA.....	110
• Wicked Problems and the CCA.....	113
• Recommendation.....	117
 Conclusion	 118
 Works Cited	 120

Introduction and Overview

The inspiration for this thesis came from my own experience as someone with impairments that some would consider classifies me as disabled, while others would not. Growing up I knew there were things about my body that made me different and resulted in lots of doctors' appointments, but I never 'felt' disabled. I also do not 'look' disabled and it is unlikely that someone who does not know me well would ascribe me to this social category. As I grew up and schooling became more intensive, my awareness of my physical impairments increased. In some situations, it was important for me to hide my impairments so as to not appear different or that my work should be valued any differently than that of my peers. However, I also knew that because of the differences of my body in comparison to others, some things that would be natural for others in a school environment would be harder for me; as such, I was entitled to certain accommodations and had to learn to self-advocate to ensure that I received the accommodations I needed. Because my impairments are not visually recognizable and have unique effects on how my body functions and learns, I spent more time trying to prove I have a disability than fighting the social stigma against having a disability.

Despite advocating for my status as someone with a disability, I still did not personally identify as someone who is disabled. This conundrum led me to contemplate how society responds to impairment, who gets to check the 'disabled box', and more importantly, what *should* the normative and political response to impairments be. Thus, the inspiration for this work was born. Importantly, I consider my personal connection to this issue as a source of inspiration and a quality within myself that provides me with a heightened ability to understand and contemplate social and political responses to impairments. However, it is not my desire for this thesis to be merely treated as a personal account of disability.

My thesis seeks to explore the relationship between biological impairments and socially constructed disabilities, as well as society's obligation to respond to disability. To do so, different perspectives on the origin of disability, such as the medical model versus the social constructionist model, will be considered. The social constructionist model of disability will be highlighted, and different theories on the ethics of disability will be evaluated from the theorists Martha Nussbaum, Iris M. Young, and Eva Kittay.

I will argue that Eva Kittay's arguments in support of care ethics best address the relationship between disability and society and how society should respond to certain impairments that are seen to cause disability. While I focus on how Kittay's care ethics, source of human dignity, and understanding of equality, are more impactful when a social constructionist model of disability is agreed upon, this approach is not necessary for the validity of Kittay's arguments to hold. Thus, the claims argued for in this paper are also compatible with a medical model of disability.

Utilizing the philosophical framework of care ethics, specifically as it relates to disability, relevant political policies will be evaluated as a means to implement care ethics within society. Policies inspired by the same values and goals that constitute care ethics, such as Paid Family Leave (PFL) and the Community Choice Act (CCA), will be highlighted and their capacity to improve the ability of disabled people to thrive will be emphasized. The political theory of wicked problems and the issue-attention cycle will be used to evaluate the quality of PFL and CCA policies as well as identify relevant political dynamics and realities. Failure to comprehensively evaluate policies using political theory and determine pertinent variables would result in a policy with good intentions but poor application, mitigating the effectiveness of the policy.

Chapter 1: A Social Constructionist Model of Disability

Introduction to the Social Construction Model of Disability

Disability can come in many forms and have various effects on the body and how people perceive that body to function in the world. Disability has been largely discussed in the context of those who have impairments, with impairments being framed as “traits of the individual that he or she cannot readily alter”.¹ This framework is general and broad, leaving room for different interpretations as to what can and cannot be classified as an impairment. However, there is a general understanding that impairments are typically a biological attribute, or a change in the body obtained throughout life, someone has that impairs their ability to meet their everyday needs. As such, the attribute of hair color is not an impairment, because different hair color is a trait that does not limit a person’s ability to thrive in society. A hearing loss would be considered an impairment because those with a hearing loss, versus those who do not, experience increased difficulty navigating and thriving in society. Rather than try to create a comprehensive definition of impairment, theorists and activists alike have found it easier to determine what an impairment is not. For instance, poverty cannot be considered a form of impairment, even though it does impact an individual’s health and experience in society. Similarly, the common flu is not considered a impairment, even though it is debilitating, it’s duration is not long enough to be commonly considered a disability; however, a disease that has significant longevity but is not a life-long condition can be considered an impairment and treated like a disability in some cases.²

¹ David Wasserman et al., “Disability: Definitions, Models, Experience,” *Stanford Encyclopedia of Philosophy*, (2016, May 23), <https://plato.stanford.edu/entries/disability/>.

² Wasserman et al., “Disability: Definitions.”

Disability is complex, and cases of the same impairment can be addressed in different ways depending on the individual needs of the person with the disability and the societal dynamics at work. For instance, the experience of someone who has a hearing loss at a common-spoken frequency (the decibels of common speech) and is a kindergarten teacher, has completely different needs than someone who has the same hearing loss but works as a landscaper. The kindergarten teacher likely needs hearing aids to amplify the voices of their students, who often talk without directly looking at the teacher, can have muffled voices, or talk quietly due to their age. However, these hearing aids must also be sensitive enough to amplify the voices of the kindergarteners, but not the sound of the pencil sharpener across the room. Due to the nature of the hearing loss, the teacher needs hearing aids that amplifies voices and similar sounds, but to amplify every sound would drown out the very voices of the students that the teacher is trying to hear. In contrast, a landscaper with the same hearing loss may still need hearing aids to amplify tones at the common-spoken frequency, but she also needs to focus on protective equipment to protect her hearing from being further damaged by the loud noises from the equipment she uses at her job. While everyone is encouraged to use protective equipment for their hearing while operating power tools, someone who has a hearing loss must be extra cautious to preserve the hearing they do have and, depending on the cause of their hearing loss, may also be at a higher risk of losing more hearing than someone without a hearing loss. This example illuminates the nuanced variations and needs related to an impairment, as well as the varying impact an impairment can have on someone's life.

The impact that disability can have on someone's life due to the characteristics of their body and how their body is perceived by people is why the study of philosophy became

interested in theorizing about disability.³ As such, prominent philosophers in the 20th century, such as Iris Marion Young, Martha Nussbaum, and Susan Wendell, began creating theories regarding disability. These theories address the origins of disability, why disability is stigmatized, how disability should be addressed, and many other important topics. Especially in the early days of its study, the philosophy of disability found its home within the philosophy of feminism. This was partially because, like women, those who are considered disabled are often compared to the stereotypical able-bodied male in common society.⁴

One of the largest problems that the philosophy of disability has been concerned with is the origin of disability. Some view disability to be a largely medical issue, while others believe disability to be a social construction caused by the behaviors of people within society. Those who believe that disability is largely a medical issue believe that disability is founded in biological impairments that may have social consequences, but the cause of the disability is due to a biological impairment.⁵ This viewpoint frequently termed the ‘medical model’, while commonly held by a large portion of society, ignores the complexities of each specific case of disability. For instance, in the example outlined above about the kindergarten teacher and the landscaper with a hearing loss, the impact of the disability and the needs of each individual are determined by their environment and job, not merely because of their hearing loss. It is for this reason that the social model of the philosophy of disability was created. Those who believe in the social model argue that disability is created when certain atypical physical or mental characteristics are not properly addressed by society, creating challenges which result in the classification of ‘disabled’ for individuals that have those characteristics. This model understands

³ Wasserman et al., “Disability: Definitions.”

⁴ Wasserman et al., “Disability: Definitions.”

⁵ Wasserman et al., “Disability: Definitions.”

disability in a manner similar to how sex classifications (male/female/intersex) can impact someone's life. Like disability, there are qualities of sex classifications that have biological connections, but have become construed into a way of marginalizing, stigmatizing, and stereotyping people due to their perceived differences. Like sex, in order to fully understand disability, we must understand the society that has classified someone as disabled and how society can change the definition of disability in a manner which seemingly allows it to create or eliminate disability.

The impact that societal dynamics have on the classification of certain impairments as a disability is easily illustrated by considering the impact of the societal acceptance and availability of glasses. Having a visual impairment (not to the extent of blindness), before glasses became commonly available and accepted within society, would have been considered a disability. Without clear vision or the help of glasses, an individual's ability to learn, work, maintain their personal safety, and other day-to-day practices is impaired. However, society has now made glasses which can correct this biological impairment largely available and affordable. There are also very few instances where people are discriminated against for having glasses. As such, having a visual impairment that can be corrected with glasses is no longer considered a disability in common society. The nature of the biological impairment has not changed over the centuries; however, what did change was how people within society responded to the impairment and how widely available resources are to help accommodate people with a visual impairment. Acknowledging this difference is a crucial aspect as to why the social model, in comparison to the medical model, more accurately represents disability.

The glasses example also illuminates the social constructionist nature of all disabilities. While impairments are based on biological factors, societal dynamics and how people respond to

impairment is what creates disability and a lesser quality of life for those whom society views as disabled. That is not to say that people with some impairments may not experience a greater amount of pain or difficulty in their lives due to biological reasons that are independent of society; however, by people within society improperly responding to the impairment and failing to provide the proper accommodations for an individual with an impairment to thrive in their own way, society is exacerbating the pain of the individual with the impairment and creating disability.

The Impact of Resource Allocation

As seen in the glasses example, the kind and amount of resources available that help those with impairments can have an extraordinary influence on how salient an impairment is and whether or not that impairment is currently classified by society as a disability. If glasses were not readily available and fairly affordable, the impact that glasses have on eliminating visual disability would be diminished. Even a commonly used accommodation, such as hearing aids, which are readily available and semi-affordable along the spectrum of medical technology (usually under \$5,000 per hearing aid) hold a cost that is prohibitive to many individuals, despite the implementation of government programs to help subsidize these costs. As such, even if society has provided the mechanism for the impact of an impairment to be mitigated if desired, this impact is minimal if society fails to make this resource widely available, affordable, and accepted within society.

While it may appear as though making accommodations that are useful to those with certain impairments widely available and affordable would place an unfair financial burden on the majority for the sake of a small minority, many accommodations that help those with

impairments are also beneficial to those without an impairment. Consider the example of spell check, before spell check was widely used on virtually any piece of technology that we now commonly use, spell check was an accommodation that a student had to receive special permission to use in school. The use of spell check can help those with various different impairments, from learning to hearing impairments. However, to be able to use spell check, students used to have to receive an Individual Education Plan (IEP) from their school system, which almost always requires medical proof that the child has an impairment and that this accommodation would help them, before the student would be allowed to use a spell checker. This process can take months, even years, depending on how willing the school system is to provide the service, and can force families to spend a large sum of money to obtain the medical proof that is required for the IEP. Moreover, the advocate for the child usually must know about the specific accommodation they would like the child to have, the process of the IEP and what it requires, and the differences in the manner each state and school system goes about this process. This complicated, time-consuming, and expensive process was all to give a child the use of a tool that we all commonly use and enjoy today without even thinking about it or realizing that it was once a highly fought after accommodation for those with certain impairments. This situation can be applied to numerous different accommodations other than spell-check, such as emotional support dogs, captioned videos, ramps as opposed to stairs, elevators, etc. all of which have been or continue to be accommodations for those with impairments that the general population could or currently does enjoy on a regular basis without a second thought. Ergo, while some may believe that the widespread use and allocation of accommodations is unfair and unnecessary to the majority, it is quite possible that many accommodations would improve the quality of life of the majority.

Martha Nussbaum on Disability

Philosopher Martha Nussbaum believes that resources should be used to help those with impairments enjoy a higher quality of life. Nussbaum's belief in the importance of the proper use and allocation of resources stems from her theory regarding human capabilities. Nussbaum argues that there are ten fundamental categories of human capabilities that each human must be able to realize to live a fulfilled life. The ten capabilities are: life, bodily health, bodily integrity, use of the senses, imagination and thought, emotions, practical reason, affiliation to others, recognition other species, play, and control over one's environment.⁶ Nussbaum believes that "if people are below the threshold on any one of the capabilities, that is a failure of basic justice" and thus society and governments have an obligation to, as much as possible, ensure that everyone has the ability to realize all ten human capabilities.⁷

If one assumes, for the sake of the argument, that Nussbaum's capability theory is correct, her view on the importance of resources can be understood. If there is a universal standard for what a fulfilled human life looks like and requires, then society needs to supply the resources, care, and social change needed to raise everyone to the universal standard of living. If someone needs a hearing aid to have the full capacity of the human capability 'to sense', then society has an obligation to supply that person with a hearing aid. In essence, resources are the mechanism for someone with an impairment to reduce or eliminate the impairment to meet Nussbaum's standards of life within the human capabilities approach. One of the main resources that Nussbaum discusses within her book *Frontiers of Justice* is good care. Nussbaum claims

⁶ Martha Nussbaum, *Frontiers of Justice: Disability, Nationality, Species Membership* (Cambridge: Harvard, 2006), 76-77.

⁷ Nussbaum, *Frontiers of Justice*, 167.

that “given the intimate and foundational role that care plays in the lives of the cared-for, we have to say that it [good care] addresses, or should address, the entire range of the human capabilities.”⁸ While good care can be a life-changing resource for many people with impairments that can help limit the impact of their disability, the presence and use of one resource does not completely eliminate disability and bring every life up to the standards articulated within the capabilities. The structure and attitude of people within society must also change if the lives of disabled people are to improve and for the impact of their disability to be lessened. Nussbaum does address the societal nature of disability within *Frontiers of Justice* by arguing that no matter how much resource distribution, including good care, society provides, disability will still persist if societal change does not occur. For instance, no matter how much money or care is given to someone in a wheelchair, if the building they need to go to does not have an elevator, their ability to function in society is severely compromised and no amount of money given to the person in the wheelchair can change that reality.⁹ However, despite the merit of Nussbaum’s arguments regarding the impact that resources can have, problems exist within Nussbaum’s capabilities approach. These problems lie within the categories themselves and the importance that Nussbaum assigns to them.

The manner in which Nussbaum discusses and categorizes mental capabilities is just one example of how these categories can have detrimental implications on disabled people. Nussbaum believes that certain mental capacities, such as the ability use reason and apply it to one’s life, is an essential aspect of being human. Within the human capability of practical reason, Nussbaum articulates her understanding of the use of reason by stating that the human capacity to reason is to be “able to form a conception of the good and to engage in critical reflection about

⁸ Nussbaum, *Frontiers of Justice*, 169.

⁹ Nussbaum, *Frontiers of Justice*, 167.

the planning of one's life."¹⁰ It can be reasonably assumed that Nussbaum would still consider a healthy human baby who cannot reason, a human being because the baby holds the future capacity to reason. The same can be assumed of elderly humans who have lost their full capacity to reason, but once held it. However, it can also be assumed that although Nussbaum would still consider people in these stages of life human, she would also claim that they were acting less human because of their inability to fully reason. Despite these allowances, Nussbaum's capability of practical reason relies on the assumption that the significant use and application of the mental capacity to reason is a fundamental aspect of humanity, and that without the capacity to reason, a being "would probably be regarded as too strange to be human."¹¹

Many humans value their ability to reason and believe that using such a capacity is a fundamental aspect of their person. However, for many people with disabilities, the ability to reason and achieving a high enough level of reasoning to be able to critically reflect on their life is difficult if not impossible to achieve. For instance, Sesha, the daughter of philosopher Eva Kittay, has significant mental disabilities that interfere with her ability to reason. Sesha has some ability to form a conception of good and bad about some things, such as music, people, and food she does or does not like. However, it is unlikely that when faced with a complex problem Sesha would be able to apply reason to the situation and determine a good response to the problem. It is also unlikely that Sesha has the ability to use reason to evaluate and critically reflect on her own life. Under Nussbaum's definition of the human capability of practical reason, Sesha does not meet the qualifications of this capability and is, under Nussbaum's reasoning, living less of a human life as a result. However, the inability for Sesha to use reason to the extent required in

¹⁰ Nussbaum, *Frontiers of Justice*, 77.

¹¹ Martha Nussbaum, "Human Capabilities, Female Human Beings," in *Theorizing Feminisms: A Reader*, ed. Elizabeth Hackett & Anne Haslanger (New York: Oxford Univ. Press, 2006), 131.

Nussbaum's capability does not prevent Sessa from living a fulfilled life and being and acting human. Nussbaum presumes that all beings that should be considered human have the ability to fully use the capability of reason. By embracing this perspective, Nussbaum is ignoring the existence of and diminishing the lives of human beings who are not born with, or lose, the natural ability to utilize a high level of reasoning and critical thinking.

Not only are the categories of the capabilities problematic, but the value that Nussbaum assigns to these categories is also harmful. Nussbaum states that "a life without the capability in question, such a life is not a life worthy of human dignity."¹² Nussbaum elaborates further to claim that a life without the full use of multiple capabilities can be considered "not a human life at all."¹³ Thus, Nussbaum's capabilities approach fails to consider many disabled people humans renders the lives of many disabled individuals inhuman, a result which is clearly inaccurate and inhumane. For instance, Hellen Keller, who was blind and deaf, lacked two of Nussbaum's capabilities but still lived a highly successful and fulfilled human life that had a profound impact on many people's lives. Kittay's daughter Sessa may not be able to fully realize many of Nussbaum's capabilities; however, she still feels emotions on a deep level, enjoys human connection, retains as much independence as is possible, and lives a fulfilled human life. It would be amiss of Nussbaum not to consider these meaningful lives as human and to do so would irretrievably diminish the lives of disabled people and the society we live in. Nussbaum also ignores the perspectives of individuals who have the option to eliminate their impairment, such as the implantation of cochlear implants for someone with a hearing defect, but willingly chooses not to because they believe their impairment is an important aspect of their being that does not make them lesser.

¹² Nussbaum, *Frontiers of Justice*, 78.

¹³ Nussbaum, *Frontiers of Justice*, 181.

Many people with disabilities believe that their lives are better because of their disability and would not wish to change their body to eliminate the impairment if such an option was available; furthermore, many believe that creating ‘cures’ for disability that eliminate or mitigate some of the negative impacts of an impairment is discriminatory to disabled people by sending the message that their bodies are not welcome in society unless they conform their body to meet social norms. For instance, in response to a growth-promoting drug that is thought to help ‘cure’ a form of dwarfism by mitigating negative side-effects of the disease and increasing growth, a member of *Little People for America* (one of the largest organizations in the US that represents people with dwarfism) stated, “people like me are endangered and now they want to make me extinct.”¹⁴ By stating that “if we could cure her [a mentally disabled child] condition and bring her up to the capabilities threshold, that is what we would do, because it is good”¹⁵ Nussbaum is ignoring the perspective of those who do not wish to change the status of their impairment and the detrimental impact that viewing certain bodies as not fit for society can have on individuals and society as a whole.¹⁶ This binary form of thinking, that an individual is either living the ‘good life’ as a fully capable human being or not due to their capabilities denies the value of disabled lives and frames disabled people as inherently lesser than those without impairments. While Nussbaum does argue that an individual’s quality of life can vary in degrees based on how many of the capabilities they can use and to what extent they use them, Nussbaum still insists that a life without the use of a capability is lesser. This is not to say that Nussbaum’s goal of creating a list of human capabilities that societies and governments must ensure every human has

¹⁴ Emine Saner, “‘There Is a Fear That This Will Eradicate Dwarfism’: the Controversy over a New Growth Drug,” *The Guardian*, Sept 28, 2020, <https://www.theguardian.com/science/2020/sep/28/there-is-a-fear-that-this-will-eradicate-dwarfism-the-controversy-over-a-new-growth-drug>.

¹⁵ Nussbaum, *Frontiers of Justice*, 193.

¹⁶ Nussbaum, *Frontiers of Justice*, 193.

access to is not an admirable goal; however, as we will later see in Eva Kittay's arguments, the same goal of inspiring society and government to take action on matters of disability and quality of life can be achieved with the creation of more general societal goals that do not exclude people with certain impairments from the good life or humanity. Instead, by creating the capabilities theory, Nussbaum has created an idealized and universal definition of what it is to be human, to have a good life, and to have dignity. By doing so Nussbaum has taken the humanity away from disabled people and further otherized the disabled population.

Iris M. Young on Disability

In contrast with Martha Nussbaum, prominent feminist philosopher Iris Marion Young disagrees with the capabilities approach and alternatively believes that instead of focusing on the distribution of resources based on human capabilities, society should first focus on how domination and oppression impacts certain groups of society.¹⁷ Furthermore, Young also disagrees with Nussbaum's creation of an idealized universal definition of what humanity is; instead, Young believes that such a universal definition is harmful and people should be accepted as people, without trying to define what it is to be a person.

Young argues that merely focusing on resource allocation can ignore many of the issues that are important to marginalized groups, including the disabled population. While the distribution of resources may lessen the impact of some issues, it can also be a band-aid solution. In this scenario, the real problem is still present but enough of a solution has been provided for society to forget about the issue, sometimes without ever even realizing there is a larger root to the problem they are hoping to fix. Young believes that the focus on distribution, specifically the

¹⁷ Iris Young & Danielle Allen, *Justice and Politics of Difference* (Princeton: Princeton University Press, 2011), 3.

distribution of material goods, “tends to ignore the social structure and institutional context” which causes the need for redistribution in the first place.¹⁸ To avoid this mistake, society should first determine the root of the problem to properly address the issue. The root cause of many societal issues, including disability, under Young’s perspective is society itself. Under Young’s viewpoint of the social model of disability, society defines what ability is and thereby creates the group of disabled people composed of anyone who has impairments that do not fit into society’s definition of ability. Society then recognizes this different group and seeks to distribute resources to help mitigate the difference between the groups of able-bodied people and disabled people; however, this solution fails to recognize the real origin and impact of the problem. By its practices, laws, customs, and organizations, society created the definition of ability which created the group of disabled people, the number of resources an individual has is not the cause of the creation of the marginalized group. Instead of solving the problem, the distribution of resources helps blur the lines between able-bodied and disabled people and merely covers-up the real societal problem that must be addressed.

Instead of concealing the differences between marginalized groups and the majority, Young believes that “where social group differences exist and some groups are privileged while others are oppressed, social justice requires explicitly acknowledging and attending to those group differences in order to undermine oppression”.¹⁹ Therefore, instead of creating band-aid solutions that merely redistribute resources, society should focus on the root causes to societal issues by addressing difference, rather than ignoring it or seeking to eliminate it. While it is true that these two strategies could be implemented at the same time, Young believes that many redistributive policies only focus on resource allocation without also addressing the larger

¹⁸ Young, *Justice and Politics of Difference*, 15.

¹⁹ Young, *Justice and Politics of Difference*, 3.

societal issue causing the need for redistribution. Young argues that to properly understand the experience and needs of those who are members of marginalized groups, such as the disabled population, you must first acknowledge their difference and how that difference impacts them. Society often does not take this strategy in regard to social problems. Generally, society follows utilitarian principles and values impartiality and emotionless decisions based on the belief that they will create outcomes that are unbiased and best for the greatest amount of people. However, under Young's perspective, the value that people within society place on impartiality results in a denial of difference which contributes to the oppression of social groups by denying their difference and how society contributes to this difference.²⁰

In further contrast to Nussbaum's human capabilities theory which creates a universal standard of humanity, Young believes that "any definition of a human nature is dangerous because it threatens to devalue or exclude some acceptable individual desires, cultural characteristics, or ways of life."²¹ Instead of creating a universal definition of humanity to give society and governments a minimum standard to help individuals meet, Young suggests an alternative view of social justice. Young believes that society has an obligation to help individuals realize two values which contribute to the 'good life', these goals are: "(1) developing and exercising one's capacities and expressing one's experience, and (2) participating in determining one's action and the conditions of one's action."²² These societal goals still retain the positives of Nussbaum's approach, such as creating an obligation for society to help improve people's quality of life; however, missing from Young's claim is a universal definition of humanity that otherizes and dehumanizes the disabled. Young believes that the two societal goals

²⁰ Young, *Justice and Politics of Difference*, 10.

²¹ Young, *Justice and Politics of Difference*, 36.

²² Young, *Justice and Politics of Difference*, 37.

she has outlined are best met with the elimination of oppression and domination, as she views oppression and domination to be the root of the majority of societal issues. Young believes the achievement of these goals requires societal change, a fact which the allocation of resources under redistributive justice theories only cover-up while the social problem continues to persist in the shadows.

Nussbaum has since altered her view of the capabilities approach and “while she insists that a just state must make each of these [Nussbaum’s ten capabilities] available to all its citizens, she no longer insists that a person unable to exercise a capability- not because she is denied the opportunity by her government, but because she lacks the underlying capacity- is to be written off as someone who cannot live.”²³ However, Nussbaum believes that having and exercising the ten capacities is the path to the good life. As such, even if Nussbaum does not believe people should be forced to or must utilize a capacity, the very creation of a list of capacities that lead to the good life suggests that Nussbaum believes that any person who does not exercise the ten capacities, whether by choice or not, is living a lesser life. In reference to whether or not individuals should utilize all ten capacities, Nussbaum’s “view is that people should be given ample opportunities to lead a healthy lifestyle, but the choice should be left up to them.”²⁴ While this may seem like a benign and considerate statement, the underlying statement is that Nussbaum believes that someone who does not use the ten capacities is not living a healthy lifestyle; similarly, a deaf person who chooses not to fully experience the human capability of the senses by getting a cochlear implant is willingly making an unhealthy decision.

²³ Eva Kittay, *Learning from My Daughter: the Value and Care of Disabled Minds* (New York: Oxford University Press, 2019), 50.

²⁴ Nussbaum, *Frontiers of Justice*, 80.

Nussbaum seemingly cannot comprehend how a disabled life could be as fulfilling as that of someone who is able-bodied.

Eva Kittay on Disability

Philosopher Eva Kittay, the mother of a significantly disabled daughter, believes that with acceptance, proper societal care, and understanding, “a good life is within reach for people with even very significant disabilities.”²⁵ Furthermore, Kittay believes that continuously denying the quality of life experienced by some disabled people can leave the disabled population without a voice as they are constantly discounted in a form of testimonial injustice.²⁶ While Kittay believes in a strong body to soul relationship, Kittay argues that the body is granted human dignity inherently by ‘being some mother’s child’ and the impairments a body may face do not define the good that can be experienced and offered by someone. Thus, the capabilities approach is unnecessary for Kittay’s arguments. Human dignity need not be proved, justified, or taken away. Similarly, Kittay believes “impairments are disabling only in an environment that is hostile to their differences and that has been constructed to include them” but in no way does Kittay believe that a disabled life is not one that can flourish and experience joy.²⁷ Autistic writer Clare Sainsbury states that “‘normal’ people take it as a basic human right to be accepted as they are, while the rest of us are viewed only in terms of what will make us more acceptable to them.”²⁸ Nussbaum seeks to create capabilities that will bring disabled people to a ‘normal standard’ under ‘normal’ conceptions of the good life. Eva Kittay seeks to acknowledge and respect disability and those with impairments and create a world where the disabled can flourish

²⁵ Kittay, *Learning from my Daughter*, 49.

²⁶ Kittay, *Learning from my Daughter*, 115.

²⁷ Kittay, *Learning from My Daughter*, 6.

²⁸ Kittay, *Learning from My Daughter*, 25.

in their own manner on the path to their ‘good life’ without unnecessarily subjecting humanity to norms.

Both Iris Young and Eva Kittay believe that disability is a social construct created by people within societies that are composed in a manner which is exclusionary to some impairments. Moreover, Iris M. Young theorized how societal views of dependency can impact the lives of marginalized people, including the disabled. Kittay expands upon the ideas of Young by going into more depth on the concept of the social construction of dependency, specifically in relation to disabled people, what the ramifications are, and how society should respond. Young believes that dependency can be a sign of injustice, such as when women have been historically forced to be dependent to men based on societal conceptions of gender roles.²⁹ However, Young also believes that dependency does not equate marginalization. Instead, society gives undue emphasis on the importance of independency and uses the lack thereof as an excuse to marginalize a group of people.³⁰ As such, it is societal practices, not the lack of independence, that are the root cause for the marginalization of people that experience dependency. In fact, Young believes that solidarity can be achieved between people when there is a respect for individuals and their experiences as well as a recognition of mutual dependence between peoples and groups.³¹ As such, Young believes the world is a better place, not a lesser one, if the world properly recognizes the role that dependency, not to be conflated with forced dependency, plays in our individual lives and our society.

Kittay expands upon the notions of dependency and independency introduced by Young and believes that, like ability, the common definition of independence is socially constructed and

²⁹ Zuzana Uhde, “On Sources of Structural Injustice: A Feminist Reading of the Theory of Iris M. Young,” *Human Affairs* 20, no 2 (2010): 159.

³⁰ Uhde, “On Sources of Structural Injustice,” 159.

³¹ Uhde, “On Sources of Structural Injustice,” 156.

given too much societal value.³² Every person experiences dependence within their lifetime. People are physically dependent in infancy, old-age, and in times of illness or recovery. People are also dependent on others for the entirety of their lives. An employee is dependent on a boss, a student on a teacher, a spouse on a spouse, a child on a parent, etc.. Thus, focusing on and romanticizing the concept of independency ignores the dependency we all face as humans and that many disabled people face constantly. Furthermore, it also creates disability when people fail to meet societal standards of independence. This is not to say that independency should not be strived for to some extent and have a healthy balance in our lives and in society. As someone who has personally experienced disability and chronic illness, my independence has always been a goal in my treatment. Independence manifests itself in positive ways in my life. I have grown to learn my symptoms and body in a manner which allows me to control much of my life and care in a way that was previously not possible. However, I must also acknowledge that my independence has limits and seeking too much of it puts risk to my happiness and health. Without the care from those who surround me, the quality of my life would be diminished and my personal health would be at risk. Kittay is not advocating for a dismissal of independence, but that we have a healthy and realistic understanding of independence which acknowledges our dependency as humans and helps reshape our understanding and experience of both ability and disability.³³

According to Kittay, properly understanding the concepts of independence and dependence is a central aspect of the creation of a just society.³⁴ Kittay believes that if society aims “for a relative independence through the appropriate management of dependency,” a world

³² Kittay, *Learning from My Daughter*, 143.

³³ Kittay, *Learning from My Daughter*, 144.

³⁴ Kittay, *Learning from My Daughter*, 21.

can be created that properly respects, cares for, and contributes to the flourishing of all individuals regardless of impairments.³⁵ Under this perspective, Utilitarian and Kantian ideals of the greatest good for the most amount of people or the most rational action are not highly valued. Instead, an individual's ability and need to flourish is deemed an end in itself and should not be treated as merely a means.³⁶ For each individual to achieve a life where they can flourish, care is needed at some point within, or throughout, their lifetime. As such, Kittay believes that an ethics of care is needed to properly frame and understand the relationships and importance of care.

Kittay believes "an ethics of care needs to hold together a tripartite conception of care as labor, an attitude (or disposition), and a virtue" and that each of these three aspects of care must be properly navigated to benefit both the caretaker and the cared-for.³⁷ Care as a labor properly recognizes the effort and skill put into care by a caretaker. An attitude of care is a respect for the importance of the cared-for/caretaker relationship and the respect and understanding of needs that must be part of the relationship for the life of the cared-for to flourish. Care as a virtue signifies the value that both individuals and society should give to care if the proper understanding of the value of care is to be achieved.³⁸ The understanding of the three aspects of care creates a world where humanity is connected by care relationships where the end is the flourishing of the individuals that are within the care relationships.³⁹

Kittay and Nussbaum are similar in that they both advocate for human flourishing; however, Kittay places a higher value on care and its ability to respond to the individualized needs of each person so that they can reach their own version of flourishing. This concept of

³⁵ Kittay, *Learning from My Daughter*, 162.

³⁶ Kittay, *Learning from My Daughter*, 23.

³⁷ Kittay, *Learning from My Daughter*, 171.

³⁸ Kittay, *Learning from My Daughter*, 171-172.

³⁹ Kittay, *Learning from My Daughter*, 173.

individualized care that is responding to unique needs differs from Nussbaum who advocates for granting everyone access to universal standards of ‘the good life’ that may not pertain to every individual. In further contrast with the universal standards Nussbaum provides to achieve human flourishing, Kittay believes that individuals can flourish when they have access to things that they care about, as Kittay states: “things that make it worthwhile for a person to get up every morning”, their genuine needs, and legitimate wants.⁴⁰ Using Kittay’s daughter Sesha as an example, the relationship between Sesha and Eva Kittay give both individuals a reason to get up in the morning and a relationship to care about. A caregiver that meets Sesha’s needs of cleanliness, nutrition, help with movement, etc. is meeting Sesha’s genuine needs. Someone turning music on or singing to her is meeting Sesha’s legitimate wants, something that her body could live without to survive but is necessary for her to live a flourishing life. If these three different needs are met, which are often best met in care relationships, Kittay believes that every life has the possibility to flourish despite any impairments.

⁴⁰ Kittay, *Learning from My Daughter*, 178.

Chapter 2: Disability and Care Ethics

The Origin of Human Dignity

Eva Kittay's understanding of the origins of human dignity is a foundational concept that her arguments regarding disability rely upon and build off of. Kittay believes that the source of human dignity is not based on the capacity to reason, as many traditional philosophers believe; instead, Kittay believes that humans are granted dignity simply because they are 'some mothers child'.⁴¹ The relationship between a child and a parental figure is one of the strongest care relationships. As part of this relationship, the parental figure is assumed to put their needs aside for the good of the child, to provide not only the basic needs of life for the child but also to provide a fulfilling life where the child can thrive. This relationship requires love, care, respect, recognition of personhood, and many other qualities that are essential to a parental relationship. Thus, if parental figures are expected to create such a care relationship between themselves and a child, society must recognize and respect this relationship and its meaning. Parenting does not occur within a vacuum but occurs within society and requires certain attitudes and services from society. As Kittay recounts from her own personal experience as a mother of a disabled daughter, "every parent needs to work with both the child and the social world that the child enters to ensure a sense of self-respect. No child is simply the parent's own private matter."⁴² If society were to deny a person, regardless of ability, human dignity, then they would also be denying the capacity of that person to 'be some mothers child' because such a relationship requires the acknowledgement of personhood and dignity.⁴³

⁴¹ Eva Kittay, *Love's Labor: Essays on Women, Equality and Dependency* (New York: Routledge, 1999), 19.

⁴² Eva Kittay, "The Personal Is Philosophical Is Political: A Philosopher And Mother Of A Cognitively Disabled Person Sends Notes From The Battlefield." *Metaphilosophy* 40, no. 3-4 (2009): 606–27.
<https://doi.org/10.1111/j.1467-9973.2009.01600.x>.

⁴³ Kittay, "The Personal is Philosophical is Political."

It is important to note that Kittay's claim that being 'some mother's child' grants an individual human dignity does not deny human dignity to those who did not have a parental figure in their life. Kittay is instead asserting that each human is entitled to care and requires care on some level to survive infancy; thus, every human must be treated with the dignity that makes such a care relationship possible and successful in society.⁴⁴ As such, human dignity is not granted to a child by the mother, or other parental figure. Instead, human dignity is granted to each child by having the status of being born of a mother and being entitled to a care relationship which allows them to survive and thrive, regardless of whether or not they have a mothering figure or such a care relationship in their lives. Similarly, Kittay believes that every child is entitled to a fulfilling care relationship, but this does not mean that children who survived infancy but did not receive proper care are denied human dignity. Instead, human dignity is granted to the child because they hold the status of a being who was entitled to such a care relationship. Furthermore, even if it were possible for a child to be born without a mother, the inherent state of dependency of an infant would still grant the child human dignity. If society were to deny a child human dignity, it would then be impossible for any mothering figure to adequately care for a child in a dependency relationship; thus, it must be the case that the status of being 'some mother's child' is sufficient grounds to grant an individual human dignity.

Denying human dignity to someone because they are disabled and may not meet certain societal expectations or capacities renders it impossible for certain aspects of the parental relationship to be achieved, specifically the recognition of personhood and fostering a world that recognizes the personhood and needs of the child. As a result, different expectations would be placed on different parental relationships simply based on the ability of the child because society

⁴⁴ Kittay, *Learning from My Daughter*, xx.

refuses to grant the full means, in the form of recognizing the human dignity of the child, that are required to fulfill a parenting relationship.⁴⁵ However, this unjust discrepancy can be resolved if society recognizes that all human beings are ‘some mother’s child’ and thus are granted certain rights and human dignity based on their membership as being a part of, or having the capacity to be part of, such a relationship. This is not to say that there is a universal formula for caring for a child but that in order for the human dignity of each child to be granted and fulfilled, the dignity of the child must be recognized by both the parental figures and the people within society. Kittay argues that “we human beings are the sorts of beings we are because we are cared for by other human beings, and the human being’s ontological status and corresponding moral status need to be acknowledged by the larger society that make possible the work of those who do the caring required to sustain us.”⁴⁶ Thus, society must recognize relationships of care and the important role they play in every individual’s life if human dignity is to be fully realized for all humans.

Inevitable Dependency

Like human dignity and being ‘some mother’s child’, Kittay believes that experiencing dependency is a fundamental aspect of humanity. Dependency can be roughly understood as being in a state where an individual requires care to meet their daily needs. All human beings experience dependency throughout their lives, whether in infancy, at the end of their life, during periods of illness, or because of disability. Dependency can be brought by different biological factors, such as the age of the body, but can also be impacted by societal factors that either create dependency itself or fail to properly address instances of dependency and thus exacerbate the

⁴⁵ Kittay, “The Personal is Philosophical is Political.”

⁴⁶ Kittay, “The Personal is Philosophical is Political.”

state of dependency.⁴⁷ To help mitigate the impact of dependency, dependency relationships are created where a dependency worker is charged with meeting the needs of the person in need of care. These relationships can come in many forms, such as the relationship of one family member to another, a nurse to a patient, and many others.

Dependency relationships are a fundamental aspect of society that are unavoidable and often ignored and devalued. Because dependency is an inescapable aspect of humanity, similarly dependency relationships are inescapable. There are also many dependency relationships within the constructs of society, although they are not commonly considered as such. Relationships between employee to boss, student to teacher, citizen to government, renter to landlord, are all dependency relationships that are essential to our social structure. In fact, “the liberal democratic structures that appear to many as requirements for a just society, would be impossible, perhaps even inconceivable without the capacities that arise out of the necessity of dependency relationships.”⁴⁸

Despite the importance and inevitability that dependency and relationships built off of dependency play in our lives, states of dependency and dependency workers are constantly overlooked and undervalued by society. When people are in states of dependency society tends to view them as not fully human because the state of dependency is causing an undesirable “denigration of the person”.⁴⁹ This does not mean that some forms of dependency are not more socially acceptable than others. People expect and even cherish the state of a dependent newborn or child, but there is still the unspoken understanding that the life of the newborn is not a fully realized human life because of the level of the infant’s dependency. Conversely, many people

⁴⁷ Kittay, *Love’s Labor*, 29.

⁴⁸ Eva Kittay, “Centering Justice on Dependency and Recovering Freedom.” *Hypatia* 30, no. 1 (2015): 287.

⁴⁹ Eva Kittay, “From the Ethics of Care to Global Justice,” Essay. In *Justice Rooted in an Ethics of Care: Reconceiving Equality*, (Tokyo, 2011), 51.

fear and hate the stages of dependency that are associated with old age, even though it is a natural aspect of humanity. People with disabilities that experience dependency that is not associated with the beginning or end of their life are often devalued because of their dependency and their perceived inability to contribute to society. It would seem that society would dislike dependency because of its necessity and neediness; however, there are countless things which people are necessarily dependent on and need to survive that are embraced. Humans necessarily need food to survive, yet this does not create a strong dislike for food. On the contrary, culinary cuisine is embraced as an art form. It is not the neediness and necessity associated with dependency that makes it undesirable but “the disadvantages that are consequence of political, social, and economic arrangements” which devalue dependency and value independence which cause us to repel against dependency.⁵⁰ Dependency is viewed as a negative not because it is inherently negative or leads to a lesser life, but because society has put an artificial level of importance on independence that cannot be met at all stages of life and by all people; however, because people are subject to the relative norm of independence, all those who do not meet that norm are devalued.

Independence is a relative term which is given a different definition and value in different instances. While independence, like dependence, is not necessarily bad, society has put an undue value on independence which often results in those who are involved with dependency, either people in a state of dependency or dependency workers, being undervalued and forgotten. Consider the case of a woman who has been reliant on an abusive spouse for her financial security. If the woman enters the workforce she is not eliminating her dependency but trading one dependent relationship for a more desirable one. The woman is still in a dependent

⁵⁰ Kittay, “Centering Justice on Dependency and Recovering Freedom,” 290.

relationship between herself and her employer, but this relationship is hopefully more desirable than the previous dependent relationship between herself and her spouse.⁵¹ This scenario highlights the inextricably interdependent nature of our society.⁵² Dependent relationships are pervasive throughout society and serve incredibly important roles; however, the dependent nature of certain forms of the dependency relationships, such as the new dependent relationship between the woman and her boss, is often forgotten by society. Similarly, dependency relationships are routinely devalued. Society rarely considers the transformative value of good care, the efforts made by dependency workers for their charge, the means and societal attitude that is necessary for dependent relationships to be successful, and dependency workers are frequently underappreciated and underpaid.

This is not to say that independence does not play an important role in society and the lives of individuals, but that valuing independence too highly can disguise and devalue dependency. Furthermore, all dependency relations are not inherently positive. A woman who is forced into a dependent relationship with her spouse and is experiencing artificial dependency is not in a positive relationship.⁵³ Positive dependency relations occur when the relationship is addressing a preexisting state of dependency, not when the relationship itself creates dependency; moreover, both individuals in the relationship, if possible, must consent to the dependency relationship.

When dependency relations are properly valued and are not artificial, they can actually create a scenario where the dependent experiences more healthy independence. By receiving the proper care that a charge (a term coined by Kittay to refer to an individual in a dependency

⁵¹ Kittay, "Centering Justice on Dependency and Recovering Freedom," 287.

⁵² Kittay, "Centering Justice on Dependency and Recovering Freedom," 287.

⁵³ Eva Kittay, "The Ethics of Care, Dependence, and Disability," *Ratio Juris* 24, no. 1 (2011).

relationship who is in need of care) needs to flourish, including access to assistive technology, the charge can experience an increased ability to be independent in certain aspects of life. A dependency worker who truly values the well-being of their charge cares in a manner that allows the charge to function at a higher capacity if possible. While this increased ability may appear different and unusual for people who are not dependent, that does not mean that it is inherently lesser. Consider the case where a carer of someone who is not highly verbal but has fine motor skills recognizes the need for the charge to have access to assistive speech technology that translates written text into verbal speech so that the charge can better communicate. In this instance, the charge is experiencing a greater amount of independence because they can communicate, including communicating about their needs, at a higher level. While the charge is not using typical methods of verbal communication, the effect and impact of the verbal communication via assistive technology is comparable. This form of independence has a positive impact because it is increasing the well-being of the charge and the state of dependency of the charge is not being ignored.

Justice that Includes Dependency

Traditional models of justice, such as those of Rawls and Bentham, operate under a model that often assume an autonomous person that is personally independent as well as being largely independent of the structural world around them and has the full capacity to reason; however, not every human being has equal access to independence and the capacity to reason and are thus left behind in many prominent theories of justice.⁵⁴ Those who are dependent, either for the entirety of their life or for a portion of their life, are not independent or fully

⁵⁴ Kittay, "The Ethics of Care, Dependence, and Disability," 50.

autonomous. Those who have certain disabilities may not have the full capacity to exercise the ability to reason. However, this does not mean that those who experience dependency or cannot fully reason should not be considered in a theory of justice. On the contrary, people who are dependent, not fully autonomous, or cannot fully reason, are in a vulnerable position and should be expressly included within a theory of justice.⁵⁵ Theories that fail to acknowledge the concept of dependency, and therefore the importance of dependency relationships, fail to teach us what to do in situations that are prevalent throughout the human experience. “A justice-based ethics has nothing to tell us about how we ought to act toward a child, an elderly individual who has lost his capacity to make decisions for himself, or a developmentally disabled child or adult.”⁵⁶ Because traditional theories of justice presume an equal world, such theories fail to provide any clarity on situations that feature naturally unequal power imbalances due to the relationship of the individuals involved, such as the unequal relationship of power between a parent and a child. This is not to say that it is impossible for a theory of justice to adequately include and account for dependency relations within the theory, but that the existing prominent theories of justice have failed to do so.

In contrast to the traditional models of justice, Eva Kittay argues that a just society should properly consider dependency and those who experience it by providing “the fair terms of social life given our mutual and inevitable dependency and our inextricable interdependency.”⁵⁷ To do so, a society must consider inevitable dependency, the care inevitable dependency requires, and the inextricable interdependence of humans on one another.⁵⁸ We have already discussed inevitable dependency, and the care inevitable dependency requires has been referenced and will

⁵⁵ Kittay, “From the Ethics of Care to Global Justice,” 114.

⁵⁶ Kittay, “From the Ethics of Care to Global Justice,” 114.

⁵⁷ Kittay, “Centering Justice on Dependency and Recovering Freedom,” 286.

⁵⁸ Kittay, “Centering Justice on Dependency and Recovering Freedom,” 286.

be further explained. The concept of inextricable interdependency refers to the fact that all humans are engaged in care and dependency relationships, no matter what society they operate within.⁵⁹ Thus, since all of humanity experiences dependency and is part of dependency relationships, it is vital for a theory of justice to provide the means and perspective for these experiences and relationships to thrive.

Connections-Based Equality

A theory of justice as described by Kittay requires a different understanding of equality than is typically used in society or traditional theories of justice. This new version of equality includes all individuals and relationships that must be included in a theory of justice for the theory to be considered adequate and complete. To meet this need, Kittay proposes a connections-based equality which considers persons equal “as they are in connections of care and concern [and the] commonalities that characterize this relatedness.”⁶⁰ Thus, equality in terms of justice becomes not a debate about what rights are owed due to the status of being an equal, as is the case with traditional theories, but instead considers questions such as: “what are my responsibilities to others with whom I stand in specific relations and what are the responsibilities of others to me, so that I can be well cared for and have my needs addressed even as I care for and respond to the needs of those who depend on me?”⁶¹ As such, a just society understands equality as providing what is needed for the cared for to receive care and for the carers to have their own needs met while they are caring for the needs of another. This sense of equality creates a nesting set of obligations where individuals are dependent on one another to

⁵⁹ Kittay, “Centering Justice on Dependency and Recovering Freedom,” 287.

⁶⁰ Kittay, *Love’s Labor*, 28.

⁶¹ Kittay, *Love’s Labor*, 28.

receive the care they need and society is responsible for creating the environment and resources needed for the dependency relationships to be fulfilled and valued.⁶²

While Kittay's definition of equality may appear to be a limited theory that only applies in specific situations, such as the relationship between a mother and a child, and does not consider all necessary aspects of equality, when the full scale of dependency relationships is considered connections-based equality fulfills these needs. Consider the relationship between a government and a citizen. If the government imposes policies which result in the unjust incarceration of individuals, the government is failing at its obligation to treat individuals as equal with respect to their right to be cared for and to care unless their actions have warranted the just diminishment of the care that is owed to them. Furthermore, if an employer discriminates against an employee based on their gender, the employer is failing to fulfill the requirements of the dependency relationship that composes the employee/employer relationship. Thus, connections-based equality can be implemented in a vast array of situations and still include aspects of the common understanding of equality that society currently values.

An Ethic of Care

As discussed previously, dependency work and dependency relations are often undervalued by society. Another reason for this practice and why dependency work is viewed as undesirable and can lead to oppressive situations is "because it exists within a social setting that fails to foster the well-being of dependency workers and their charges."⁶³ Thus, a change in society is needed for dependency to be properly considered and understood and for dependency work to be properly valued and supported. To fulfill this need, Eva Kittay proposes an ethic of

⁶² Kittay, *Love's Labor*, 68.

⁶³ Kittay, *Love's Labor*, 96.

care.⁶⁴ This form of ethics is based on previously mentioned ideas proposed by Kittay, including the idea that human dignity is granted because someone is ‘some mother’s child’ and that a connection-based equality should be implemented that allows everyone with human dignity to be included in a theory of justice.⁶⁵

An ethic of care that properly considers dependency, dependents, and dependency workers requires society to recognize that people have an attachment to others, an empathetic attention to their needs, and a responsiveness to the needs of another.⁶⁶ Similar to the outcome of connections-based equality, in an ethic of care, nesting relationships of care and dependency are created and thus must be respected and supported by society. Kittay believes that under an ethic of care, society should be constructed in such a manner where all individuals are granted certain rights based on their inherent human dignity as ‘some mother’s child’ and their position in dependency relationships. These rights include: “the understanding that we will be cared for if we become dependent; the support we require if we have to take on the work of caring for a dependent; and the assurance that if we become dependent, someone will take on the job of caring for those who are dependent on us.”⁶⁷ For the promise of these rights to be reasonably guaranteed, society must be altered on an individual, political, and societal level to create an environment where care and dependency are acknowledged, valued, and prioritized on all levels. While an ethics of care may provide the reasons and the justification for enacting such a change, it alone cannot create change without the subsequent work of a model for care that addresses care on the individual, political, and societal level; thus, Kittay proposes a model of care which she

⁶⁴ The concept of an “ethics of care” was originally developed by Carol Gilligan to encapsulate the moral perspective held by many women in contrast to an ethics of justice, which focuses on more male-centric values.

⁶⁵ Much of the foundational philosophical work on the concept and needs of mothering was developed by Sarah Ruddick.

⁶⁶ Kittay, *Love’s Labor*, 101.

⁶⁷ Kittay, *Love’s Labor*, 102.

models after a concept she names ‘doulia’, discussed later in this chapter, to accompany an ethic of care and provide a model to enact the changes needed for an ethic of care to be implemented.

An ethic of care can be applied when either the medical model or the social constructionist model of disability is used, making it advantageous for use in political policies. Because an ethic of care is responding to disability and dependency, regardless of the origins of the disability or dependency, the values and policies supported by an ethics of care can be implemented without having to reach an agreement as to what the cause of disability is. While in Chapter One I argue in favor of a social constructionist viewpoint on the origins of disability, an ethic of care is not dependent on this belief.

While not essential, the social constructionist model of disability does provide a greater justification than the medical model for society’s obligation to support dependency relationships and provide for disabled people. Because the social constructionist model believes that disability is a social construction created by society’s inability to respond to certain differences in the human body, it logically follows that society has an obligation to rectify this injustice and respond to disability. If the medical model is followed and the origin of disability is removed from society, it can be harder to establish a sense of responsibility for society and governments to respond to disability. Although, even under the medical model, societal practices still have a direct impact on creating disability. This is because the norms that govern the medical world, such as 20/20 vision being the standard for good vision, are social constructions that are not entirely based off of biological concepts. Instead, they are social norms which determine what capabilities are normal and what capabilities classify someone as disabled. However, this can feel like a more removed connection between society and disability than the causal link that is provided under the social model; thus, without this strong link people within society can feel less

willing to institute needed change. Nevertheless, because the social constructionist model of disability is relatively unknown among the average population or can be deemed ‘too liberal’, it may be advantageous to propose political policies that are supported by an ethic of care without specific reference to the social construction of disability. In this scenario dependency relationships and disability are still being addressed by society and quality care is being valued, all of which contribute to the well-being of both the charge and the carer.

The Roles and Needs of Dependency Work

For dependency relationships to be as successful and effective as possible, two different roles, the cared for and the carer, need to be supported and acknowledged by society. The cared for, or ‘charge’ as Kittay refers, has the obligation to receive care gracefully when warranted and possible.⁶⁸ By acknowledging the care that is being done on their behalf, the charge is acknowledging the importance of the dependency work and the effort that is required by the carer to provide quality care that contributes to the well-being of the charge; moreover, the charge is also acknowledging the dependency relationship and reciprocating the work of the carer by fulfilling their own role of accepting care when needed. This acknowledgement supports the relationship and also highlights the existence of dependency relationships in society. The thanks, or acknowledgement of care, does not have to be in traditional forms and may not be possible for all charges. Forms of thanks could include a form of physical affection such as a hug, verbal gratitude, a smile, or different type of interaction between the cared for and the carer. However, when such forms of interaction are not possible for the charge, such as if the charge is an infant, the charge is not obligated to acknowledge their gratitude in this manner.

⁶⁸ Kittay, *Learning from My Daughter*, 185.

While acknowledging the work of the carer and accepting care may seem like an unimportant event, graciously accepting care can entirely alter the success of a care relationship. In my own experience as someone who has needed care in my life, there were certainly many times where I did not receive care with grace. Instead, I responded with anger and frustration, refusing or not acknowledging the care from those who were offering it. This created a relationship of animosity between my carer and myself. I did not want to receive care, which I am sure did not make it an enjoyable or rewarding experience to care for me. Thus, a wall was built in the dependency relationship and the quality of care I received because of this lack of connection decreased. In contrast, when I received care with grace and gratitude, such as from family members I trusted, I was acknowledging and fostering the growth of the care relationship. This created a scenario where I received better care, my happiness increased, and the work of my carer was more fulfilling when their care was well received and acknowledged with gratitude.

While the charge may be obligated by being part of a dependency relationship to receive care with gratitude when the relationship is just, this does not mean that the charge is always obligated to accept and be grateful for the care they are offered. Kittay believes there are three main instances where the charge is not obligated to accept the care they are being offered.⁶⁹ The first of these situations occurs when the carer perceives a need for care but the need is non-existent or the charge does not desire to receive care. In order to avoid a paternalistic form of care, the charge must be free to deny care when they are not in need of it or if they simply do not wish to receive care.⁷⁰ When possible, the charge must still maintain the agency of their own bodies, forcing care upon the charge denies agency. Similarly, when care is not needed but is

⁶⁹ Kittay, *Learning from My Daughter*, 216.

⁷⁰ Kittay, *Learning from My Daughter*, 216.

forced, a suppressive artificial dependency relationship can be created where an individual is unjustly forced to be dependent upon their carer for no legitimate reason.

The second reason why Kittay believes care can be justly refused is when the care is offered in good faith, but the carer is incompetent at providing the care. While having good intentions when providing care is necessary, it is not sufficient. Good care must include sincere motivations as well as the proper skills needed to provide the care. When care is offered without the proper skills, the “discomfort, humiliation, and outright mortal danger” of the charge are all possible with varying degrees of severity.⁷¹ Thus, the care could actually increase the dependency of the charge and decrease their quality of life. As decreasing the severity of dependency and its negative ramifications, as well as increasing the quality of life of the charge, are the goals of a dependency relationship, the charge is under no obligation to accept the care when such goals will not be met.

The third scenario in which, according to Kittay, a charge can justly refuse care is if the care that is being offered by the carer is not sincere or offered in good faith. When care is offered as a means to an end where the end is not the happiness and increase in quality of life of the cared for, the care should not be accepted.⁷² Care that is not offered with the flourishing of the cared for in mind can harm the charge and does not respect dependency relationships.

A carer also has their own obligations to fulfil as part of their role in a dependency relationship. The first is to be motivated to care for an individual to enhance their well-being for their own sake as its own ends. Such a motivation is an important aspect of the ethics of care which creates the foundation of a successful dependency relationship. As discussed above, if a

⁷¹ Kittay, *Learning from My Daughter*, 217.

⁷² Kittay, *Learning from My Daughter*, 217.

carer has the wrong motivations for giving care, the life of the charge can be negatively impacted and the dependency relationship can be disrespected and diminished.

Kittay also believes that care is an action word and that “to care (for or about) or to be a caring person is to engage in caring activities or to be prepared to engage in actions that such care demands.”⁷³ Thus, to care requires executing caring actions with the proper motivations to guide the actions that are being undertaken. These actions must be desired, if possible, by the charge and be in the best interest of the well-being of the charge. Care must be tailored to account for the complexities of each unique situation, charge, and dependency relationship; however, in general, “an action will count as care if it contributes to the well-being, restoration or flourishing of a being or a subject.”⁷⁴

For the needed care actions to be possible and contribute to the flourishing of the charge, the carer must have certain skills that are required for the care to be possible.⁷⁵ Care can require various different levels of skills. The skills needed may be common, such as the ability to cook or interact with someone in a meaningful way. They can also require extensive medical training, such as the training that is required of professional nurses and doctors who care for those who are dependent on them. Without this care, the charge can be negatively impacted and the felt impact of their dependency can increase.

Kittay also believes that care is an ‘achievement verb’. Thus, for an action to be properly considered care, it must achieve its goal to increase the well-being of the individual being cared for. While motivations are an incredibly important aspect of care, they are not sufficient. If I have the motivations to make my dog happy and increase her well-being but I ignorantly give her

⁷³ Kittay, *Learning from My Daughter*, 189.

⁷⁴ Kittay, *Learning from My Daughter*, 191.

⁷⁵ Kittay, *Learning from My Daughter*, 190.

chocolate which harms her in an attempt to act on my admirable motivations, my action towards my dog cannot be considered an act of care. That is not to say that good cannot result out of failed care, but that the care that was needed was not fully provided.⁷⁶ However, the achievement of care can be a slightly nuanced concept. For instance, if the specific goal of a care action is to decrease the pain of an individual but, due to reasons outside of the control of the carer or the cared for, the pain cannot be lessened, it is possible that the individual feels a form of relief and appreciation that at least an effort towards the lessening of their pain was attempted.⁷⁷ Thus, the individual is better-off thanks to the actions of their carer, even if the primary goal of relieving pain was not achieved. In these situations, it can still be said that care was achieved, but the extent to which the care was achieved is lesser in comparison to if the pain of the charge could have been lessened by the carer.

While there are many aspects of caring that the carer can control themselves, some needs that are necessary for a successful care relationship are out of the control of an individual carer and can only be provided by society. For a dependency relationship to be successful, a carer must have the power and authority needed to properly care for their charge.⁷⁸ If the carer is constantly undermined by society and their role as a carer is not taken seriously, it will be impossible for the carer to provide the highest level of care for their charge. If a carer, who knows their charge and their needs well, knows that their charge's well-being would be increased if they had access to some form of technology, but the carer is not in a position of power and authority where their opinion is valued, it is unlikely that the charge will receive the care that will increase their well-being to the fullest extent. For instance, consider the situation of a mother going through the IEP

⁷⁶ Kittay, *Learning from My Daughter*, 192.

⁷⁷ Kittay, *Learning from My Daughter*, 192.

⁷⁸ Kittay, *Love's Labor*, 3.

process for their child to get services in school so that their child can get the same quality of education as their peers. In this situation, there is an unequal power relationship where the mother has less power than the school principal and other officials who represent the side of the school. While the mother may know her child and their needs best, because of the unequal power relationship where the school officials have more authority than the mother, who is the carer in this scenario, unless the mother knows the IEP process and its nuances very well, the likelihood of the child receiving the services they need is significantly less than if there was an equal power relationship between the mother and the school officials.

The lack of quality pay and worker's benefits for care workers, when they are paid, as they often are not, is a clear indication that society does not properly value and give the needed power and authority to dependency workers.⁷⁹ Care workers are constantly underpaid and overworked. Moreover, dependency work is disproportionately allocated to women and specifically impoverished women or women of color.⁸⁰ As such, these women are put into a position where their work is not valued by society and the pay they receive reflects that fact. The unequal division of care labor thus serves to further disenfranchise the already suppressed groups of impoverished women and women of color. This creates a situation where dependency work is forced onto certain groups of people, whether directly or indirectly in various different forms, such as tradition. While dependency work is necessary in society, it should always be willingly undertaken by an individual and supported by society; otherwise, the very labor that supports the flourishing of humanity can become a suppressive force.⁸¹

⁷⁹ Kittay, *Love's Labor*, 98.

⁸⁰ Kittay, *Love's Labor*, 98.

⁸¹ Kittay, *Love's Labor*, 99.

Both the carer and cared for are subject to vulnerability due to their position in the dependency relationship; thus, society and the individual people within the dependency relationship must acknowledge this vulnerability to prevent it from becoming exploitative.⁸² The charge is most obviously vulnerable to their carer, as the achievement of their needs and often their life is in the hands of their carer. Thus, if the caretaker purposely or accidentally mistreats the charge, the charge may have little power to stop this mistreatment due to the nature of their dependency. Moreover, because of the dependency of the charge, the carer has more power in the dependency relationship. If this unequal power relationship turns exploitative and the charge is taken advantage of, due to the power imbalance between the charge and the carer, it is unlikely that the charge has the means to prevent the exploitation. A carer also often serves as an advocate for the charge; thus, if the carer does not properly advocate for the needs and desires of the charge, the charge can be left without a voice and their needs would remain unfulfilled.

While less immediately obvious, the carer is also vulnerable to the charge in a dependency relationship.⁸³ Because a carer is tasked with meeting the needs of a charge, if the charge manufactures false needs or allocates too much work to the carer at once, the carer can feel obligated to fulfill these needs and powerless to refuse the work due to their role in the dependency relationship.⁸⁴ The vulnerability of the carer to the demands of the charge can be increased when there is a societal power imbalance between the carer and the charge.⁸⁵ For instance, if the carer is in a position of poverty, an immigrant, member of a racial minority, etc., and the charge is wealthy and white, the carer can feel dominated by the needs of the charge and powerless to assert their own authority due to the higher social position of the charge. What must

⁸² Kittay, *Love's Labor*, 34.

⁸³ Kittay, *Love's Labor*, 34.

⁸⁴ Kittay, *Love's Labor*, 34.

⁸⁵ Kittay, *Love's Labor*, 35.

be kept in mind is that the carer is ‘some mother’s child’ as well as the charge. Thus, the carer has the same entitlement to care and having their needs met as the charge. Therefore, if the charge is demanding too much care or abusing the dependency relationship, the needs of the carer are not being met and they are not being placed in an environment where they can flourish. This situation places the dependency worker in a position of secondary dependency where their ability to have their own needs met is diminished simply because of their role as a carer.⁸⁶ In order to avoid this scenario, not only does the charge have the responsibility to respect the carer when possible, but society also has an obligation to support the dependency relationship to ensure it enhances the flourishing of both the carer and the charge. As stated by Kittay, if dependency work “is oppressive, it is so because it exists within a social setting that fails to foster the well-being of dependency workers and their charges.”⁸⁷ To create an environment where both the charge and the carer can thrive and flourish, Kittay proposes that society operate within the principle of *doulia*, which is a principle of care created and supported by Kittay.

Doulia as a Model for Care

For dependency relationships to be properly supported and valued by society they must be supported by political policies. While a connections-based understanding of equality and an ethic of care both contribute to the overarching success of dependency relationships, for these concepts to be fully realized in society they must be supported and implemented within political policies. To do so, Kittay suggests that political policies be enacted based on the concept she terms ‘*doulia*’. *Doulia* is a principle of care based off of a revised version of the Greek

⁸⁶ Kittay, *Love’s Labor*, 46.

⁸⁷ Kittay, *Love’s Labor*, 96.

conception of a doula, which originally referred to a slave or servant.⁸⁸ Kittay changes the meaning of this term to instead refer to “an arrangement by which service is passed on so that those who become needy by virtue of tending to those in need can be cared for as well.”⁸⁹ This creates a nested set of dependency relationships that respects both carers and care takers, unlike the relationship referred to in the original term of doula. In her revised version of doulia, Kittay believes that “just as we have required care to survive and thrive, so we need to provide conditions that allow others- including those who do the work of caring- to receive the care they need to survive and thrive.”⁹⁰ According to Kittay, one of the most influential ways to implement the concept of doulia within society is by enacting political policies that align with the values supported in Kittay’s concept of the doulia. The major example of policy reform that Kittay suggests is the expansion of welfare programs to provide compensation for dependency workers.⁹¹ Kittay believes that with the enactment of an expanded welfare program, dependency relationships will be better supported and valued by society and three main issues that relate to dependency relationships are mitigated.

Kittay’s belief in the need for state support for the well-being of disabled people and those in dependency relationships is similar to Nussbaum’s call for governmental action to ensure that everyone has access to the ten human capabilities; however, Kittay believes that governmental and societal support should be granted in a general manner to support dependency relations and those within them so that resources are available to cater to the individual needs of each charge to help facilitate the charge’s individual version of human flourishing. This perspective differs from Nussbaum’s claim that governmental support should be implemented so

⁸⁸ Kittay, *Love’s Labor*, 107.

⁸⁹ Kittay, *Love’s Labor*, 107.

⁹⁰ Kittay, *Love’s Labor*, 107.

⁹¹ Kittay, *Love’s Labor*, 128.

that all humans have access to the same universal capabilities regardless of whether or not that capability is desirable or achievable for each individual.

For the concept of *doulia* to be supported, Kittay believes that “all dependency work, whether it is care for children, the ill, the aged or the disabled, must be recognized as social contributions which require reciprocation, not for the cared for but by a larger social circle in which the dependency relation is embedded.”⁹² This recognition and societal support for dependency workers is necessary because dependency workers are placed in a position of secondary dependency. This occurs because by making sure her charges’ needs are being met, the dependency worker is inherently put into a position where they are vulnerable to both the power and needs of the charge as well as their undervalued position in society as a carer.⁹³ While it may seem like there is nothing inherent to a dependency relationship that diminishes the ability for a carer to meet their own needs, there are countless common instances of this scenario occurring within society. As Kittay begins her book *Love’s Labor* recounting, we all know a mother who puts the needs of those who rely upon her above her own, even to the extent that her own needs are no longer being met.⁹⁴ The same result can be said about teachers who spend their own money and unpaid time to make sure the children in their class have what they need to thrive in a learning environment, and countless other examples where carers sacrifice the achievement of their own needs for the sake of the well-being of those in their care. Furthermore, as the term ‘charge’ is defined, the charge alone is unable to provide their carer with the same extent of care to reciprocate the care that is being given to the charge by the carer. To account for this transactional imbalance, society must therefore compensate the dependency worker to ensure

⁹² Kittay, *Love’s Labor*, 140-141.

⁹³ Kittay, *Love’s Labor*, 128.

⁹⁴ Kittay, *Love’s Labor*, 23-26.

that the needs of the dependency worker are met, as they have just as much entitlement to have their needs met as the charge does.⁹⁵ By expanding welfare programs to compensate dependency workers, society is fulfilling their obligation to ensure that the dependency worker can have their own needs met and not be negatively impacted due to their position in a dependency relationship.

The second issue that an increased welfare program addresses is Kittay's belief that "an economically self-reliant provider/caregiver model requires a rate of compensation that makes it viable for a provider to support a family."⁹⁶ In essence, in a capitalistic society, individuals are not provided by the government with the means necessary to ensure their basic survival. Thus, the workforce must provide a mechanism for those who work, including in dependency work, to receive enough compensation that they can support themselves and those who are reliant on them.⁹⁷ In our current society, dependency work is frequently left unpaid or is poorly paid. This leaves carers in a situation where they are not able to meet their own needs, let alone the needs of those who depend on them. However, if political policies were enacted that compensated carers for their work at a rate that is proportionate to the value of their work and the impact it has on society, carers and those who rely on them would have the needed means to meet their needs.

It is partially due to the negative economic position many carer's face that Kittay proposes the third issue that would be mitigated by an increased welfare program. The third issue relating to dependency work is that such work "disadvantages the dependency worker with respect to her (or his) exit options."⁹⁸ This problem can manifest itself when a carer has to be reliant on someone outside the care relationship for their needs to be met. Due to the lack of pay for dependency work, many carers are reliant on a spouse or other family member to meet their

⁹⁵ Kittay, *Love's Labor*, 144.

⁹⁶ Kittay, *Love's Labor*, 141.

⁹⁷ Kittay, *Love's Labor*, 143.

⁹⁸ Kittay, *Love's Labor*, 141.

own needs, primarily their economic needs. Thus, because their current job does not meet their economic needs, carers are forced to either change their occupation or be reliant on another. As such, if the relationship between the carer and those who provides care for them becomes unhealthy, the carer can be trapped in the relationship due to the inability of the carer to receive adequate pay for their work in our current society. Moreover, because dependency work is currently primarily assigned to women, the forced economic dependency of many carers disproportionately suppresses women. However, this problem is mitigated if dependency workers are compensated for their work and do not have to be reliant on others for their economic needs to be met.⁹⁹

While the concept of someone being dependent on another for their needs to be met may not immediately appear to be a negative, or could in fact be considered positive under Kittay's viewpoint, the scenario above describes artificially forced dependency with no alternative option. This situation is not supported by Kittay, who instead believes that everyone should be entitled to receive the care they deserve and that they choose to have in the manner in which they choose to receive it, within reason, in order for the agency of the individual to be protected. As such, the dependency worker should have the ability to leave the unhealthy relationship and be able to have other viable options to meet their needs outside of the relationship.

While there are other political policies that could be enacted that follow the concept of *doulia*, the compensation of dependency work by the expansion of welfare policies would have a substantial impact on how society views and values dependency work, increase the well-being of dependency workers and their position in society and the workforce, and would allow concepts such as connections-based equality to be realized. However, the current state of policy regarding

⁹⁹ Kittay, *Love's Labor*, 142.

disability and dependency work in the United States makes it unlikely that such a progressive policy as compensating for dependency work would be enacted in the near future. However, policies such as Paid Family Leave (PFL) and the Community Choice Act (CCA) are more politically realistic and would help implement the concept of doulia and increase the well-being of carers, charges, and society alike. When considering the implementation of such policies it is important to utilize political theories, such as the theory of wicked problems and the issue-attention cycle, to help evaluate whether or not the policy would have a positive impact on society and what political realities may complicate the implementation of the policy.

Chapter 3: Conceptualizing Political Policies

Background to Wicked Problems

Before discussing which political policies best implement the ideals and goals outlined in Kittay's philosophical concept of *doulia*, it is first necessary to explore some of the political theories that can be used to evaluate public policy. Political theories help provide important frameworks that not only help critique different aspects of a policy, but also provide reasoning for why political problems exist and why certain solutions, rather than others, are proposed. For instance, Rittel and Weber's theory "Wicked Problems" helps identify why certain political problems are hard to solve, what circumstances lead to the creation of such problems, and what should be included in political policies attempting to lessen the impact of a 'wicked problem'.¹⁰⁰ Such theories seek to acknowledge different social complexities, needs, trends in human behavior, and political and economic realities.

Upon coining the term 'wicked problems' Rittel and Weber sought to identify what circumstances lead to the creation of a wicked problem. Based on their analysis, the creation of wicked problems stems from a complicated combination of human psychology and political and economic realities; however, wicked problems have often persisted throughout history, only becoming slightly more or less salient in different centuries. That being said, Rittel and Weber did identify a main cause of wicked problems in the modern world- the prevalence of valuing efficiency when planning political policies and solutions.¹⁰¹

When creating a political policy, it is important to consider what values should have the greatest influence on the policy. For instance, if the primary goal of a policy is to decrease the

¹⁰⁰ Horst W J Rittel, and Melvin M Webber, "Dilemmas in a General Theory of Planning," *Policy Sciences* 4 (1973): 155–69.

¹⁰¹ Rittel and Webber, "Dilemmas in General Theory of Planning," 158.

amount of people that experience food scarcity, and equity and moral values are given the highest priority, the policy could increase access to food stamps despite the rise in cost that such a policy would demand. However, under the same scenario, if being fiscally conservative was valued higher than equity, the policy would likely target the reallocation of the current money being spent on food stamps in order to target people with the greatest need instead of expanding the program. Rittel and Webber argue that strongly valuing efficiency in these scenarios increases the salience of wicked problems.

When efficiency is valued in the context of political policies it often comes at the cost of quality. When planning a political policy, it is necessary to consider different social needs, how different groups of people will be impacted by the policy, if the policy is supported by the general public and politicians, how much of an economic impact it will have, will other policies suffer if this policy is enacted, and lots of other complex considerations. For instance, if a policy is enacted to support industry in a certain area that has high unemployment rates, on the surface this might appear to be a good policy; however, what may not be known is that encouraging business development in one area may hurt businesses and employees in a neighboring region if the policy is not carefully enacted. Moreover, if the proposed area of development is near wetlands, ecosystems could be permanently damaged by the increase in development. Such potential and obscure ramifications could easily be overlooked or never even considered if the main value of the policy is efficiency.

While efficiency to some extent can be a positive value to keep costs low and to streamline a policy, valuing efficiency too highly is detrimental. As Rittel and Weber state, with an increased value put on efficiency when making political policies, planning for such policies turned into merely “a process of designing problem-solutions that might be installed and

operated cheaply.”¹⁰² As a result, many political policies came to incorporate less of what the *right* thing to do was, and instead morphed into policies that merely fixed the problem enough with minimal cost. The lack of truly addressing problems, as well as the ever-prevalent existence of complicated social problems, created an interconnected chain of social problems with no clear source or end. Thus, wicked problems arise where a clear solution may not be possible, and the interconnected nature of the problem makes it hard to address the root cause. Despite the significant impact of wicked problems, society grew to accept their existence and lack of solvency, creating a world where “we are now sensitized to the waves of repercussions generated by a problem-solving action directed to any node in the network, and we are no longer surprised to find it inducing problems of greater severity at some other node.”¹⁰³ This is not to say that all wicked problems arose from a lack of attention or too much focus on efficiency. Some wicked problems, such as poverty, have always plagued society and continuously resurface in different ways. Others arise due to lack of political agreement, strained budgets, prejudice, and many more reasons. However, despite the cause of a wicked problem, which may not be able to be determined, all wicked problems share similar commonalities.

Defining Wicked Problems

Wicked problems are difficult to address because of their nature, which lacks a specific attainable and measurable goal. For many wicked problems, they simply cannot be solved and “at best they are only re-solved- over and over again.”¹⁰⁴ This separates wicked problems from the scientific and mathematical realm and categorizes them as social problems. To help identify

¹⁰² Rittel and Webber, “Dilemmas in General Theory of Planning,” 158.

¹⁰³ Rittel and Webber, “Dilemmas in General Theory of Planning,” 159.

¹⁰⁴ Rittel and Webber, “Dilemmas in General Theory of Planning,” 160.

and understand the complexities of wicked problems, Rittel and Webber identified ten different qualities that wicked problems share. Rittel and Webber also coined the term ‘wicked problems’ not to suggest that the problems are evil or malicious, but instead malignant and tricky, to warn political policy planners as to the nature and significance of wicked problems.¹⁰⁵

The first quality of a wicked problem that Rittel and Webber identify is that “there is no definitive formulation of a wicked problem.”¹⁰⁶ Meaning, there is no clear way to summarize the background information needed to properly understand the wicked problem and how it should be addressed. Instead, information about the wicked problem is subjective and how it can be presented and understood depends on the perspective of those gathering the background information and those processing such information. Some wicked problems are also too large to properly summarize and determine a solution for. Consider the wicked problem of why people with disabilities are not properly represented in the workforce. Depending on whether or not the person gathering background information on the topic believes in the social constructionist or medical model of disability would entirely alter the information that was deemed relevant. If they subscribed to the medical model, the focus would be on gathering information on healthcare, insurance costs, availability of accessible technology, and other related issues; however, if they believed in the social constructionist model, the focus could be on the quality of education people with disabilities receive, the housing available to them, discrimination they may have faced, etc.. It is also clear to see how expansive the background information that is relevant to this topic is and how difficult it would be to truly understand all pertinent aspects of the problem when trying to create a political solution.

¹⁰⁵ Rittel and Webber, “Dilemmas in General Theory of Planning,” 160-161.

¹⁰⁶ Rittel and Webber, “Dilemmas in General Theory of Planning,” 161.

The second aspect of a wicked problem that Rittel and Webber identify is that “wicked problems have no stopping rule.”¹⁰⁷ Mathematical problems typically have a clear process and a clear end; however, wicked problems have no clear end because they are subjective and linked to so many different issues. Consider the case of trying to improve the number of people with disabilities in the workforce outlined above. If the quality of healthcare for people with disabilities is improved, while this would provide benefits to people with disabilities and likely improve their employment rates, it does not ‘solve’ the problem. Under this scenario people with disabilities could still receive inadequate educations, experience prejudice in the workforce, etc.. As a result, political planners cannot hope to solve a wicked problem, only to make it better and decrease its salience. This reality can make it difficult to gain political approval and support for plans addressing wicked problems and make it even less likely for the wicked problem to be properly addressed.

The third quality of wicked problems that Rittel and Webber address is that “solutions to wicked problems are not true-or-false, but good-or-bad.”¹⁰⁸ Unlike mathematical problems, where a strategy to solve the problem will either result in a true or false answer, proposed solutions to wicked problems cannot be so easily evaluated. Instead, solutions to wicked problems are varying levels of good and bad. A policy that improves healthcare for people with disabilities in hopes of increasing employment rates is likely a good policy. Is this policy the best it could have been? Likely not, but it is also probably not the worst. Such considerations must be used when evaluating solutions to wicked problems instead of continuously searching for the ‘true’ answer to the problem that completely rectifies the issue.

¹⁰⁷ Rittel and Webber, “Dilemmas in General Theory of Planning,” 162.

¹⁰⁸ Rittel and Webber, “Dilemmas in General Theory of Planning,” 162.

The fact that there is “no immediate and no ultimate test of a solution to a wicked problem” is the fourth quality of wicked problems that Rittel and Weber identify.¹⁰⁹ Proposed solutions to wicked problems cannot be easily tested, and often years must pass before the outcomes of a political policy addressing a wicked problem can be truly addressed. As such, it can be difficult to weigh the pros and cons of a political policy that is related to a wicked problem. For instance, if a healthcare policy is enacted to try to improve care for those with disabilities, it could easily take years for the policy to be fully enacted and many years after that to try to determine whether or not the policy has a positive influence on the employment rate of people with disabilities.

The fifth quality of wicked problems that Rittel and Weber discuss is that “every solution to a wicked problem is a ‘one-shot operation’; because there is no opportunity to learn by trial-and-error, every attempt counts significantly.”¹¹⁰ This is because each attempted solution to a wicked problem leaves a trace that cannot be undone; therefore, applying the strategy of trying lots of different solutions to a wicked problem to hopefully determine which one is the best is not a viable option as each solution would leave a lasting impact that would possibly make the wicked problem worse or change the nature of the problem. Moreover, because it often takes years before enacted solutions to wicked problems can be evaluated, learning by trial-and-error would be an incredibly lengthy process.

The sixth aspect of wicked problems that Rittel and Weber ascertain is that “wicked problems do not have an enumerable (or an exhaustively describable) set of potential solutions, nor is there a well-described set of permissible operations that may be incorporated into the

¹⁰⁹ Rittel and Webber, “Dilemmas in General Theory of Planning,” 163.

¹¹⁰ Rittel and Webber, “Dilemmas in General Theory of Planning,” 163.

plan.”¹¹¹ In chess, there is a finite number of moves that can be considered when attempting to reach a goal. However, wicked problems have an infinite number of solutions that can be attempted to lessen the salience of the wicked problem. There can always be different ways of tackling the problem, different versions of the same strategy, alterations in application of the policy, etc.. As such, it is difficult to have assurance that the best course of action is being undertaken when trying to address a wicked problem; which in turn makes it difficult to raise public or political support for a policy addressing a wicked problem. This lack of reassurance about a proposed policy can also lead to an incredibly prolonged planning process when trying to create a policy that addresses a wicked problem.

The fact that “every wicked problem is essentially unique” is the seventh quality of wicked problems addressed by Rittel and Weber.¹¹² Because wicked problems are so complex and have complicated and extensive histories, no one wicked problem is directly comparable to another. As such, it is impossible to truly compare different solutions used in response to one wicked problem when trying to plan a way to address a different wicked problem. For instance, it may seem like there may be similarities between addressing unemployment levels of people with disabilities and veterans; thus, making it possible to apply the lessons learned from one population to the other. Although the targeted populations are very different, both populations encounter social forces that make it harder for members of the population to get and maintain a job. However, the background of each of these wicked problems is incredibly different and while some information from one scenario could be applied to another, the majority of the aspects of a policy addressing a wicked problem must be tailored to fit the needs of each specific wicked problem. Furthermore, it is hard to divide wicked problems into specific groups where each

¹¹¹ Rittel and Webber, “Dilemmas in General Theory of Planning,” 164.

¹¹² Rittel and Webber, “Dilemmas in General Theory of Planning,” 164.

problem in the group shares certain qualities and can best be addressed in certain ways. Both of these complications associated with wicked problems eliminate many of the strategies often used when trying to plan a policy to address a specific issue; as such, those who are tasked with addressing wicked problems are thrown into new territory where the previous experience they have learned and strategies they have successfully used may no longer be applicable.

The eighth aspect of wicked problems that Rittel and Weber address is that “every wicked problem can be considered to be a symptom of another problem.”¹¹³ Successful political policies often address a problem at its root, rather than merely treating the symptoms of the problem; however, the root of a wicked problem often leads to another wicked problem, creating a cycle where the root of a problem is impossible to determine. This aspect of wicked problems makes it difficult to create a large lasting impact on improving a wicked problem, as a deeper, complex problem underlies all wicked problems. For example, one root problem of low employment rates of people with disabilities is the social stigma against people with disabilities, which can also be connected to the high value that society places on independence, which can then be traced to problems associated with a capitalistic society, and so the cycle continues. Furthermore, the social stigma against people with disabilities is not the only root of the wicked problem of low unemployment rates of people with disabilities. It could also be said that inadequate healthcare, the structure of the workforce, values of society, and other problems could be aspects of the root of the problem. As such, it is incredibly difficult to create a comprehensive and impactful policy that addresses a wicked problem.

The ninth quality of wicked problems that Rittel and Weber discuss is that “the existence of a discrepancy representing a wicked problem can be explained in numerous ways. The choice

¹¹³ Rittel and Webber, “Dilemmas in General Theory of Planning,” 165.

of explanation determines the nature of the problem's resolution."¹¹⁴ Similar to the first quality of wicked problems, that they have no definitive formulation, the cause of wicked problems can be explained in numerous different ways that are dependent on the perspective of the party explaining the wicked problem. As such, wicked problems can be presented in numerous different ways that can result in the confusion both of policy planners and the general public. Such confusion can also stall the planning process as differing parties argue as to whose interpretation of the cause of the wicked problem is correct.

The final quality of wicked problems that Rittel and Weber discuss is that the planner attempting to reduce the salience of the wicked problem "has no right to be wrong."¹¹⁵ Proposing numerous hypotheses that result in incorrect answers is expected and is often left unpunished in the scientific world. However, policy planners who propose solutions to wicked problems that end up having a negative result are not given such leeway. Because of how much wicked problems impact society, the number of people they effect, and the long-term consequences of enacting a policy addressing wicked problems, solutions are expected to have only positive repercussions and any negatives are harshly criticized. While engaging in criticism of policies that result in harms is beneficial and necessary for the improvement of the political system, criticism that is not realistic and does not consider the complicated nature of wicked problems, or places too much blame on one individual, can result in more negative rather than positive repercussions.

¹¹⁴ Rittel and Webber, "Dilemmas in General Theory of Planning," 166.

¹¹⁵ Rittel and Webber, "Dilemmas in General Theory of Planning," 166.

Solutions to Wicked Problems

The ten qualities of wicked problems listed above may make it appear as though no real work can be done to minimize the impact that wicked problems have on society; however, although some wicked problems will realistically always be present, the impact that they have on society can be lessened by enacting appropriate public policies. To do so, certain considerations and realistic expectations are necessary for policies to be successful and decrease the amount of societal harm caused by wicked problems.

The first step in enacting a successful policy addressing a wicked problem is to recognize the complexity of the wicked problem being addressed. As outlined above, wicked problems are inherently complex and have no clear end or beginning. Instead, wicked problems are cyclical and lead into each other, creating an intermeshed entanglement of causes and effects. Moreover, wicked problems are subjective and how they are presented, understood, and what causes of the wicked problem that are identified all depend on the perspective of the party who is presenting information. As such, policy planners must devote the time and resources needed to properly understand the wicked problem being addressed. Due to the extensive nature of wicked problems, it may be impossible to fully understand the background of the problem; however, creating a comprehensive brief on the problem, its causes, those who are affected by it, and different proposed solutions is possible and, when done properly, increases the effectivity of policies that address wicked problems. Furthermore, those who are debating which policy to enact when addressing a wicked problem must also bear in mind the complex nature of wicked problems and understand that while there may not be a perfect solution to wicked problems, wicked problems must still be addressed with the highest quality political policies available. Lastly, the general public must also be aware of the complex nature of wicked policies. This

understanding is important for the public to understand the realities of wicked problems, the difficult task assigned to policy planners when attempting to address a wicked issue, and the high quality of policy-work that wicked problems require.

Inadequate solutions to wicked problems can have wicked ramifications, with the possibility of making the problem even worse than before the solution was enacted. This is because there is no way to test solutions to wicked problems and there is no right or wrong answer regarding which solution would best address a wicked problem. Each wicked problem is unique, which makes it hard to determine what policy would best address a problem by merely comparing similar solutions that have already been enacted to address wicked problems; however, there is some important information that can be gleaned from policies that have already been enacted to address wicked problems. Such is the case when the wicked in question is similar enough to the wicked problem being addressed by a current political policy that a like comparison can be made. In such situations, it is beneficial to determine the similarities and differences between the two wicked problems, the details of the policy that has been enacted, and whether or not that policy has had a positive or negative impact on the wicked problem. When such an analysis has been completed, it can be inferred as to whether or not, given the differences between the two wicked problems, the solution to one wicked problem would have positive impacts on a similar wicked problem.

Consider a case where a hypothetical policy that improved healthcare for disabled people was enacted in Vermont. After years of implementing and gathering data on the policy, it was determined that the policy had a positive impact on the employment rate of people with disabilities in Vermont. Taking this information into consideration, the state legislature of Texas wants to address a similar wicked problem of increasing the employment rate of people with

disabilities in Texas. Texas then determines the differences between the two states and their residents, while also taking into consideration the data from the comparable policy enacted in Vermont. As a result of this analysis, the state legislature of Texas decides to implement a similar version of the Vermont plan, with necessary changes included that address the differing needs of the two states. In this scenario, Texas is using the resources and knowledge that is already available to help create the best policy addressing a wicked problem. Although the issue of unemployment of people with disabilities in Vermont and in Texas are two different wicked problems with different backgrounds, needs, and complexities, the similarities between the two problems create an opportunity where one state can learn from another.

It is also important for all involved parties to note that while a perfect solution to a wicked problem may not exist, significant improvements to wicked problems can be made if well thought-out policies are enacted to address it. As a result, the salience of the wicked problem lessens and the amount of people who are negatively impacted by the wicked problem decrease. For instance, the enactment of policies such as Paid Family Leave and the Community Choice Act, discussed in the subsequent chapters, would have a positive impact on decreasing various different wicked problems and increasing the happiness and quality of life of many people. Thus, despite the complex nature of wicked problems, policy makers and the public alike should always strive to address and decrease the salience of wicked problems.

The Issue-Attention Cycle

Similar to Rittel and Weber's theory of wicked problems, the issue-attention cycle is another political theory that was created by Anthony Downs.¹¹⁶ The theory of the issue-attention

¹¹⁶ Anthony Downs, "Up and Down with Ecology-the Issue-attention Cycle," *Public Interest* 28 (1972): 38-50.

cycle seeks to answer the question as to why certain issues are brought to the public light and receive attention, only to later be left unresolved and fall out of the media cycle. Anthony Downs argues that an issue receives media attention and focus from the public not necessarily because the problem has just arisen or new information has been discovered, but because of the “nature of certain domestic problems and in the way major communications media interact with the public.”¹¹⁷ Similarly, Downs argues in his theory that just because a problem has left the focus of the media and the public, should not necessarily infer that the problem has been resolved. It is this process of problems coming in and out of popularity, while being left unresolved, that Downs terms the ‘issue-attention cycle’. Properly understanding the issue-attention cycle, and what problems are likely to be subjected to it, can help political planners best determine how to solve an issue and the social forces at work that might prevent them from doing so.

There are five main stages of the issue attention cycle that Downs identifies. The first stage is the “pre-problem stage.”¹¹⁸ At this point, the problem exists and has been identified by experts in the field; however, it has failed to receive recognition by the general public or major news sources. Interestingly, the state of the problem at this stage is often worse than in later stages of the issue-attention cycle when the problem has gained awareness. One example of an issue at the pre-problem stage occurred before the mid-1960’s when the poor living conditions, inadequate care, and egregious actions that mental institutions took towards their patients was identified and experts called for changes; however, the issue failed to gain wide-spread public support and media coverage until several years later.

¹¹⁷ Anthony Downs, “Up and Down with Ecology-the Issue-attention Cycle,” 39.

¹¹⁸ Anthony Downs, “Up and Down with Ecology-the Issue-attention Cycle,” 39.

The second stage of the issue-attention cycle is “alarmed discovery and euphoric enthusiasm” as the public ‘discovers’ the problem and develops a passion for rectifying it.¹¹⁹ Such a sudden discovery often comes in the wake of a significant event that highlights the problem that was previously hidden from the public view. As a result of the discovery of the problem, sections of the public then experience an extreme sense of interest and commitment to solving the problem; thus, media coverage, public knowledge, academic writing, and the social prevalence of the problem all increase dramatically. Moreover, the problem also gains traction in the political realm as the public pushes for change targeted at solving the issue. Following the enthusiasm of the public, politicians will often make unrealistic claims about their ability to solve the problem, even if the problem is incredibly complicated, or wicked. In response to the sudden call for change to rectify the problem, opposition to such change also rises just as fast. Thus, debates on the topic begin to frequent dinner tables, debate stages, and newsrooms.

The third stage of the issue-attention cycle that Downs identifies occurs when the public realizes “the cost of significant progress.”¹²⁰ This process occurs gradually as the public learns more about the problem and becomes increasingly invested in its solvency, as such information also comes with knowledge of the political and economic realities associated with the issue. Often the problems that are victim to the issue-attention cycle are complex social problems that have various different offshoots and impact a large amount of people; thus, solving such problems typically requires a substantial amount of time, commitment, and money. During this stage the public is still gaining knowledge about the problem that may spark more enthusiasm; however, the new information gathered also starts to concern less exciting information that contains more information regarding the details of the problem or difficulties around solving it.

¹¹⁹ Anthony Downs, “Up and Down with Ecology-the Issue-attention Cycle,” 39.

¹²⁰ Anthony Downs, “Up and Down with Ecology-the Issue-attention Cycle,” 39.

At this point, the public's commitment to the identified problem begins to plateau or wain as realities settle in and the fourth stage of the issue-attention cycle, the "gradual decline of intense public interest", begins.¹²¹ The problem has now left the dream world and is placed solidly in reality as politicians debate potential solutions and try to determine where to find the needed funds. It is also likely that during this stage the true complexity of the problem is revealed and politicians and the general public alike both become overwhelmed when contemplating how to solve the problem. Moreover, by identifying the cause of the problem, many individuals are less likely to be invested in solving the problem if they realize they will have to give up something for the problem to be solved, or if they are in some way blamed for the cause of the problem. Additionally, the problem becomes less exciting and more boring as headlines become less about important new developments and instead increasingly feature duller details such as academic reports, the lack of progress of a proposed legislative bill, or economic analyses. The problem can also become boring as the public grows desensitized to the problem and headlines that would have once inspired riots now only receive a brief uproar. Lastly, it is likely that by this point in the issue-attention cycle, another problem has entered into the beginning stages of the cycle and is stealing the public and media attention that was previously allocated to the problem at hand. The combination of all these factors causes public support for the problem and the media coverage that is devoted to the topic to slowly decrease.

The fifth and final stage in the issue-attention cycle is the "post-problem stage."¹²² At this point, the original problem has lost the majority of its public support and media coverage and has been almost fully replaced by another problem that has caught the public eye. However, the status of the problem has also morphed in comparison to its status prior to stage two of the issue-

¹²¹ Anthony Downs, "Up and Down with Ecology-the Issue-attention Cycle," 39.

¹²² Anthony Downs, "Up and Down with Ecology-the Issue-attention Cycle," 40.

attention cycle. This is because “during the time that interest was sharply focused on this problem, new institutions, programs, and policies may have been created to solve it. These entities almost always persist and often have some impact even after public attention has shifted.”¹²³ As such, even if the efforts devoted to solving the issue were not significant enough to completely solve the problem, it is likely that some advances have been made to improve the status quo. However, it is also possible that the efforts that were devoted to the problem backfired and had a negative impact on the problem, rendering it worse-off than it was before it entered the issue-attention cycle. In either case, because of the popularity they once had, problems that have gone through the issue-attention cycle will likely go through future periods of varying levels of popularity as the issues relating to the problem sporadically occur.

In order to predict on some level which social and political problems have a higher likelihood of encountering the issue-attention cycle, Anthony Downs identifies three qualities that many problems that get caught up in the issue-attention cycle possess. The first of these qualities is that “the majority of persons in society are not suffering from the problem nearly as much as some minority.”¹²⁴ Because the majority of the population is not directly involved or impacted by the problem, the likelihood of the problem catching and maintaining the public eye is decreased. For instance, people are inevitably placed in scenarios where they are dependent on someone or someone is dependent on them due to inevitable dependency, as explained by Kittay. As such, it can easily be presumed that many people would care about issues of dependency and making sure that charges and carers receive needed accommodations. However, many people are only carers or charges for a relatively short period of time; as such, a carer may become passionate about issues surrounding Paid Family Leave while they are caring for a sick spouse,

¹²³ Anthony Downs, “Up and Down with Ecology-the Issue-attention Cycle,” 41.

¹²⁴ Anthony Downs, “Up and Down with Ecology-the Issue-attention Cycle,” 41.

but when the spouse recovers their enthusiasm for such political policies decreases and becomes less relevant to the individual.

The second quality that Downs identifies in many problems that are subject to the issue-attention cycle is that “sufferings caused by the problem are generated by social arrangements that provide significant benefits to a majority or a powerful minority of the population.”¹²⁵ As such, there are forces at work that are motivated to suppress the uprising of the problem, and only when an egregious event occurs or the minority that is harmed gains a rare moment in the spotlight does the problem surface. For instance, it is often cheaper for builders to design and build buildings that are not accessible to people with various different disabilities. It is not in the builder’s best interest for the lack of accessibility of most buildings to be brought to the public attention, creating a powerful force that is invested in suppressing this problem. As such, the news fails to highlight this injustice and the general public is largely unaware of the negative impacts of this problem. Only when an individual is personally impacted by the lack of accessibility of many buildings, or a significant court case arises, does the issue surface and gain attention.

The third quality of many problems that encounter the issue-attention cycle that Downs identifies is that “the problem has no intrinsically exciting qualities-or no longer has them.”¹²⁶ Problems constantly compete for media attention and the passion of the general population. There are simply too many problems and not enough airtime to cover them; as such, problems must be engaging and dramatic in order to catch and maintain the attention of the media and general public for an extended period of time. Many problems can gain this attention for a short amount of time, say after a significant event that results in riots; however, the ability for a

¹²⁵ Anthony Downs, “Up and Down with Ecology-the Issue-attention Cycle,” 41.

¹²⁶ Anthony Downs, “Up and Down with Ecology-the Issue-attention Cycle,” 41.

problem to maintain such attention is rare. As a result, problems that are constantly and dramatically changing, such as war or major elections, receive the greatest amount of attention. In contrast, problems that have sporadic but inconsistent dramatic events are often subject to the issue-attention cycle.

Chapter 4: Paid Family Leave

Introduction to Paid Family Leave

Thousands of Americans are in positions such as Eva Kittay and are unofficially tasked with providing care for a loved one, either for an extended or temporary period of time. Furthermore, many individuals experience personal health problems that persist overtime, or their condition may be unique enough, such as chronic fatigue, that they do not qualify for typical employee medical leave programs. Whether an individual is caring for another or themselves, an extreme amount of time, money, and energy is typically required for the carer to provide proper care to the charge. This makes it difficult for caretakers and those with a medical condition themselves to both work and provide the care that their loved ones or they themselves need. Thus, the need for a national Paid Family Leave (PFL) program is created.

Paid Family Leave programs differ in the exact details of each program; however, most PFL programs are designed to provide nonprofessional caregivers and those who need personal medical leave with the opportunity to apply to receive a portion of their pay for a period of time while they are on leave from their employment. This allows individuals to receive the financial support and time they need to effectively give and receive care. Without PFL, many individuals are at risk of losing their job due to taking time off to care for loved ones or themselves. Moreover, PFL provides consistent financial support to individuals during trying times when they are often paying for medical expenses and are unable to work. Without the ability to take PFL, many people lose their job, are not able to receive the care they need, provide the needed level of care to loved ones, and encounter significant financial hardship due to the health of their loved ones or their own health.

The Family Medical Leave Act

While there is no national Paid Family Leave Act, the Family Medical Leave Act (FMLA) was enacted on a national level in 1993 to at least provide some options for a select group of people who are in caring roles or need care themselves. The FMLA provides some individuals with the ability to receive up to 12 weeks of unpaid leave per year with the same health benefits as if they were working.¹²⁷ FMLA also mandates that individuals must be able to return to their job, or an equivalent job, at their workplace at the end of their leave and cannot be fired simply for taking leave.¹²⁸ Individuals can apply for FMLA for a variety of reasons, including: for the birth of a child, for the adoption or fostering of a child, to care for an immediate family member with a serious medical condition, for personal medical leave for a serious health condition, or for select reasons if an immediate family member is in active service.¹²⁹

The passage of the Family Medical Leave Act was part of the fourth and fifth stage of Paid Family Leave's journey through the issue-attention cycle. The need for PFL has always existed and been known by a select few; however, it was not until the issue received national attention after a push from relevant non-profit organizations that the idea of PFL began to receive recognition and support from the general public. As the public began to learn of the benefits of enacting PFL, they also learned of the perceived cost and damages the program would cause. As such, instead of passing a more comprehensive paid leave plan, FMLA was passed. Although FMLA was still a revolutionary and progressive policy when it was enacted, the passage of FMLA did not solve or even address many of the wicked problems that create the

¹²⁷ "Family Medical Leave Act," U.S. Department of Labor, www.dol.gov/agencies/whd/fmla.

¹²⁸ U.S. Department of Labor, "Family Medical Leave Act."

¹²⁹ U.S. Department of Labor, "Family Medical Leave Act."

need for a paid leave program. Instead, FMLA produced a false sense of solvency which resulted in public attention shifting away from the issue, signaling the end of PFL's journey through the issue-attention cycle; however, this was not the end of the story for PFL. After several years, the public has again started to become aware of the need for PFL and the problems with the current federal FMLA policy.

As stated by Kittay, "while the Family and Medical Leave Act is an immensely important piece of legislation, the law is relatively limited in its scope and in the real benefits it provides. Consequently, its contribution to fair equality for all is circumscribed."¹³⁰ Many of FMLA's failures relate to the limited population that is eligible for the program. For instance, only employees who work for a covered employer, have worked 1,250 hours during the 12 months prior to taking leave (not including paid time off or any type of leave), work at a company where the employer has 50 or more employees within a 75 mile radius, and have worked for the employer for at least 12 months, can qualify for leave under FMLA.¹³¹ Moreover, although FMLA is a federal program, it places a lot of power within the hands of the employer to reject applications for leave. Under FMLA employers can require an employee to obtain medical proof of the reason they are applying for leave with only 15 days of notice, when many doctors' appointments take months to schedule. Moreover, even if the requested medical proof is obtained, an employer can find the proof unsatisfactory and only give the employee 7 days to rectify any problems.¹³² Additionally, employers can require a second or third medical opinion from different doctors to verify the medical condition and its extent.¹³³ An employer can also request the recertification of the medical condition every 30 days, or even sooner if the employer

¹³⁰ Kittay, *Love's Labor*, 135.

¹³¹ U.S. Department of Labor, "Family Medical Leave Act."

¹³² U.S. Department of Labor, "Family Medical Leave Act."

¹³³ U.S. Department of Labor, "Family Medical Leave Act."

asks to extend the period of leave, forcing the employee to restart the entire certification process.¹³⁴

As a result of these restrictions and the power given to employers over an employee's ability to take leave, the effectiveness of FMLA is decreased. Many people who work at small businesses, businesses that mainly operate online or remotely, and many others cannot qualify to receive FMLA. Additionally, the certification processes to receive FMLA can be incredibly hard to navigate, time consuming, and expensive when the cost of multiple doctors' appointments is considered. Possibly the most significant negative aspect of FMLA is that it is unpaid. Without pay, many individuals cannot afford to take the time off that they need, especially at a time where they are likely having to pay expensive medical bills. Even if employees can take unpaid time off, a significant amount of financial and personal stress is added to the employee's life that could impair their ability to give and receive care. Despite the enactment of FMLA, "to take time off from work to attend to a sick child then remains a luxury or a factor moving one closer to impoverishment".¹³⁵ As such, many individual states have recognized the gaps within the current FMLA policy and have implemented their own PFL programs, which better align with Kittay's concept of a doulia, to help support the residents of their state.

Case Study: Paid Family Leave in Connecticut

Connecticut recognized the need for Paid Family Leave based on gaps in FMLA and the fact that currently only 17% of workers and 6% of low-wage workers, who are disproportionately women and people of color, have access to paid family and medical leave.¹³⁶

¹³⁴ U.S. Department of Labor, "Family Medical Leave Act."

¹³⁵ Kittay, *Love's Labor*, 138.

¹³⁶ CT Campaign for Paid Family Leave, CWEALF, Accessed January 6th, 2020, <https://paidfamilyleavect.org/>.

To accomplish this goal, various different PFL programs have been advocated for by the non-profit organization *the Campaign for Paid Family Leave*, other organizations, lawmakers, and residents of Connecticut since 2013.¹³⁷ This resulted in various different bills concerning PFL being discussed in the state legislature; however, these bills failed to pass both the state House and Senate until 2019. In 2019 legislative session the CT state legislature passed Public Act No. 19-25: An Act Concerning Paid Family and Medical Leave, which “creates a statewide system of job protected paid leave to workers who need to take time off to care for themselves or a loved one, or welcome a new child”.¹³⁸ The passage of Public Act No. 19-25 added Connecticut to the list of ten states that have passed a PFL program, with the CT PFL program being one of the most comprehensive.¹³⁹

The Connecticut PFL program offers eligible individuals to apply for 12 weeks of paid leave, with the option of applying for 2 additional weeks if it is in response to a serious health condition that occurred during pregnancy.¹⁴⁰ Leave can either be taken for a continuous stretch of time or intermittently throughout the year. The CT PFL program is available to individuals who are employed by a business of one or more employees. All businesses with 1+ employees are included in the state plan, while those who are self-employed or are a sole proprietor have to individually opt-in to the program.¹⁴¹ Additionally, employees must have earned wages, including salary, hourly, vacation, holiday, severance pay or tips and commissions, totaling of at least \$2,325 in the highest quarter of the first four of five most recently completed quarters.¹⁴² Lastly, individuals must be currently employed or have been employed within the last 12 weeks.

¹³⁷ CWEALF, CT Campaign for Paid Family Leave.

¹³⁸ CWEALF, CT Campaign for Paid Family Leave.

¹³⁹ CWEALF, CT Campaign for Paid Family Leave.

¹⁴⁰ Connecticut Paid Family & Medical Leave, CTPFMLA, 2020, https://ctpaidleave.org/s/?language=en_US

¹⁴¹ CTPFMLA, Connecticut Paid Family & Medical Leave.

¹⁴² CTPFMLA, Connecticut Paid Family & Medical Leave.

Employees can apply to receive PFL for a variety of different reasons. 12 weeks of leave can be taken to care for a new child, whether the child was brought into the family by birth, adoption, or foster care. An additional two weeks can be taken if a serious health condition was caused by pregnancy.¹⁴³ Leave can also be taken if the employee or a family member has a serious health condition or is an organ or bone marrow donor. Recognizing the impact of domestic violence, the CT PFL plan is also available for those impacted by family violence to seek physical or psychological care, relocate, or participate in civil or criminal proceedings relating to family violence.¹⁴⁴ Lastly, if a family member has been injured while on active duty, or simply if a member of the family is serving in active duty, family members can take PFL to care for the injured service member or to care and maintain their family while the individual is on active duty.¹⁴⁵ Under the CT PFL plan, a ‘family member’ is a member of an individual’s immediate family, grandparent, grandchild, or an individual who is related by blood or affinity whose relationship to the employee is equivalent to that of a family relationship.

As part of the benefits of receiving the PFL program in CT, individuals receive a portion of their pay during their time of leave. If an individual’s wages are less than or equal to the CT minimum wage multiplied by 40 per week (which is currently equal to \$520 weekly), then the employee will receive 95% of their average weekly wage as part of the PFL program.¹⁴⁶ If an employee makes more than the CT minimum wage multiplied by 40 per week, the weekly benefit under the PFL plan will be 95% of the CT minimum wage multiplied by 40, plus 60% of the amount the employees wage exceeds the CT minimum wage (capped at 60 times the CT

¹⁴³ CTPFMLA, Connecticut Paid Family & Medical Leave.

¹⁴⁴ CTPFMLA, Connecticut Paid Family & Medical Leave.

¹⁴⁵ CTPFMLA, Connecticut Paid Family & Medical Leave.

¹⁴⁶ CTPFMLA, Connecticut Paid Family & Medical Leave.

minimum wage, which is currently \$780 weekly).¹⁴⁷ This financial support provides income to employees at a rate roughly comparable to their normal pay, which greatly reduces the financial stress employees normally experience during times when they need to take PFL. The funds for the PFL program are collected by payroll deductions which began January 1st, 2021 and are capped at 0.5% of an employee's wage. These funds are then pooled into a single trust managed by the state treasurer and funds will be allocated to PFL applications beginning in January 1st, 2022 after enough funds have been gathered in 2021 to create a pool to draw from.¹⁴⁸

Benefits to Implementing Paid Family Leave

The benefits to implementing paid family leave help mitigate the problems left unaddressed by FMLA and can be compiled into three main categories: the benefits to the charge, the carer, and society. The rationalization for these benefits is provided by the philosophical arguments raised by Eva Kittay and explained throughout the second chapter of this thesis.

By enacting a paid family leave program, the inevitable state of dependency of the individuals receiving care is recognized and supported, and the quality and individualization of their care is improved. As articulated by Kittay, all individuals experience dependency throughout their lifetimes in various different forms; as such, all individuals need various forms of care to address their dependency in a manner that fosters the flourishing of the charge. While some states of dependency require constant professional care, many instances of dependency are best addressed and cared for by family members and friends. For instance, consider the case of a woman who is recovering from surgery on her knee. She does not need constant care in a

¹⁴⁷ CTPFMLA, Connecticut Paid Family & Medical Leave.

¹⁴⁸ CTPFMLA, Connecticut Paid Family & Medical Leave.

professional care facility, but she is still unable to meet many of her basic needs due to her limited mobility and requires help from others to ensure that she can go to necessary post-surgery medical appointments, physical therapy, and various other needs that ensure she heals effectively and efficiently. Without a PFL program, not only is it a possibility that the woman would not have been able to take paid time off for her own surgery and be at risk of losing her job and financial security if she did complete the surgery, but she would also be unable to receive the care she needs to properly recover because her family members would be unable to take time off of work to provide the care she needs. As a result, the woman either does not have the surgery for fear of losing her job and livelihood, or has the surgery and risks losing her job and does not have proper care during the recovery process, further extending the amount of time she is dependent and must be away from work. However, if PFL is enacted, the woman can take paid time off of work while she recovers from the surgery, while knowing her job is protected during her recovery. Additionally, family members could take PFL to care for the woman and provide her with the care she needs to recover. This example shows how PFL programs respect the various inevitable states of dependency that all humans encounter by providing a mechanism for those who need care to take the time off of work that they need to care for their medical needs related to their dependency, while also providing a mechanism for the charge to receive care from their loved ones in a manner which respects the needs of the charge and the carer.

For states of dependency that do not have to be addressed by a professional care facility, the ability to receive care from a loved one can often be the highest quality and best received care available to a charge. As stated by Kittay, “in our dependency, we not only require care, but require a sustaining relation with a care-giver who provides us this care- for who does the caring

is often as important as the care itself”.¹⁴⁹ A perfect example that highlights the importance of the person giving the care is the relationship between a mother and a newborn. PFL programs allow the mother to take time off to recover from pregnancy, provide needed care for her child, and to bond with the baby. After implementing PFL in California, it was found that more new mothers took leave, which led to an increased immunization rate, well-baby checkups, increased likelihood and duration of breastfeeding, increased parental involvement, and a decreased prevalence of pre-term births.¹⁵⁰ These positive outcomes occurred because mothers could take the time they personally needed to recover from birth and did not have to worry about fitting doctors’ appointments and other needed care for their baby into their work schedule. PFL programs would not just benefit infants and mothers, but also offers the ability for loved ones to provide needed and personal care to their loved ones of any age who are experiencing dependency. As a result of the connection shared by the charge and the carer when they are family members, it is likely that the care will be well received by the charge and that the carer will be invested in the personalized care and flourishing of the charge as an ends of itself, and not merely a means. Such a connection and individualized level of care is difficult to achieve from a carer who is not personally connected to the charge, or if the care is being administered in a large care facility such as a nursing home. However, without PFL the ability to give and receive care from loved ones is a luxury only those in a state of privilege can enjoy.

Paid Family Leave programs also provide benefits to carers by respecting the obligation that carers have to their charge, the needs of the carer, as well as other practical benefits. By providing carers with pay and job protection while they take time off of work to care for a loved

¹⁴⁹ Eva Kittay, “Taking Dependency Seriously: The Family and Medical Leave Act,” 8.

¹⁵⁰ Tara O’Neill Hayes and Margaret Barnhorst, “How Children Benefit from Paid Family Leave Policies,” American Action Forum, June 9, 2020.

one, the government is supporting the dependency relationships that create a connections-based equality. Connections-based equality understands equality as providing what is needed for the cared for to receive care and for the carers to have their own needs met while they are caring for the needs of another. This sense of equality creates a nesting set of obligations where individuals are dependent on one another to receive the care they need, and society is responsible for creating the environment and resources needed for dependency relationships to be fulfilled and valued.¹⁵¹ PFL programs help foster a society where dependency relationships are valued and carers have the resources and protections needed to care for their charge effectively. Without PFL, the work of carers is discounted and often never seen or acknowledged, let alone compensated, by the government or society. Instead, thousands of carers take unpaid time off of work or quit their job to help care for loved ones. Those who do not have such options are forced to watch while their loved one suffers from not receiving proper care because their family members lack the financial security required to offer their care to the charge. However, if society acknowledged these common dependency relationships and provided carers with paid family leave, carers would be in a more equitable position where they could fulfill their obligations as part of a connections-based equality without jeopardizing their own personal lives and financial security.

By providing financial support to caregivers the government is supporting dependency relationships and providing a mechanism for the needs of the dependency relationship to be fulfilled. Much like many interactions, there is an aspect of a dependency relationship that is transactional. A dependency worker provides care for the charge, in return the charge either accepts the care with gratitude or denies the care. However, unlike most transactional

¹⁵¹ Kittay, *Love's Labor*, 68.

relationships in the workforce, the charge is often unable, due to their state of dependency, to provide monetary compensation to the dependency worker in response to their care. In this common scenario, “it is the duty of the State, whether it is the provider [of the care] or not, to be sure that the work is well done and that the dependency worker is compensated.”¹⁵² PFL provides a mechanism for the state to fulfill its role in a dependency relationship and ensure that the dependency worker’s actions do not go unpaid. If dependency work is left unpaid this would minimize the commitment, both in time, energy, and finances, that dependency workers make to their charges and the incredibly positive impact that adequate care from a loved one can have on a charge’s life and ability to flourish. While not all examples of dependency work are covered by most proposed or enacted PFL programs and some dependency work would be left unpaid even if a national PFL program was enacted, PFL would still provide compensation to many dependency workers and would improve the current status quo.

There are also numerous practical benefits that PFL could have on dependency workers that should not be forgotten. Providing dependency workers with job protection and financial support by enacting PFL makes it possible for many more family members to take time off of work to care for their loved ones, a possibility that is not an option for many who depend on their salary to provide for themselves and others, and whom do not have existing adequate job protections provided by their employer or state. This provides a way for carers to maintain their presence in the workforce, even while they are giving care. As a result, workers in states with PFL tend to remain in the workforce instead of quitting their job to care for a loved one, and also receive higher wages overtime.¹⁵³ This means that those who are dependent on the carer who is

¹⁵² Kittay, *Love’s Labor*, 144.

¹⁵³ CT Campaign for Paid Family Leave, CWEALF.

currently providing care for a loved one are also positively impacted by PFL because they do not have to suffer from the loss of the carer's income that they are dependent on.

Moreover, if a carer can take PFL their own health needs are positively impacted. PFL would provide relief to thousands of people who either would like to care for a loved one and cannot due to their employment situation or those who are carers and who are suffering financially because of the care they are providing for a loved one. The elimination of this large mental stress on thousands of individuals is not a small impact to be forgotten. Moreover, a carer is more likely to take time for their own health and needed doctors' appointments while they are also providing care for a loved one if they have a more flexible schedule and continuous financial support provided by a PFL program.

There are also societal benefits that would be felt if Paid Family Leave was implemented. PFL provides families and carers with needed support during a relatively short period of time when they are in need, which in turn allows the carers and their families to maintain their financial independence and place in the workforce. This impact can be seen in various different tangible and measurable outcomes; for instance, "women who return to work after a paid leave have 39% lower likelihood of receiving public assistance and a 40% lower likelihood of food stamp receipt in the year following the child's birth."¹⁵⁴ This is because PFL programs allow women to take the time they need to recover from pregnancy and care for their child without having to leave the workforce or go without a steady income. Additionally, workers who take PFL have a greater chance of earning higher long-term wages than those who were forced to leave their job to receive or provide care and then return to the workforce.¹⁵⁵ This increases the

¹⁵⁴ CT Campaign for Paid Family Leave, CWEALF.

¹⁵⁵ CT Campaign for Paid Family Leave, CWEALF.

financial stability of many families and decreases the likelihood that they will have to rely on government funds to meet their basic needs.

Other societal benefits to implementing PFL are less tangible but would still have a significant positive impact on society. By enacting PFL and supporting dependency relationships, society is acknowledging the presence of dependency and the obligations that are associated with properly responding to states of dependency. By creating a clear path for carers to take when they need to care for their loved one, dependency relationships will begin to become normalized within society. This normalization will help decrease the stigma against dependency as society becomes accustomed to confronting and responding to dependency in public, rather than in private homes without the knowledge of others. As more workers begin to take paid leave to care for their loved ones, the presence of dependency and its obligations will become more obvious than if the employee did not take leave. For instance, if a father has to take paid family leave to care for his sick child, the workplace becomes aware of the father's situation. Because the father is taking leave and not quitting his job to care for his child, the workplace has the opportunity to acknowledge the father's role as a carer for his child and will be motivated to formulate a plan as to how to best balance the father's obligation to his child and his duties as a member of the workforce. As more individuals take leave for reasons similar to those of the father explained above and more workplaces become aware of dependency relationships and different ways to address them, dependency will start to become more normalized in society. Moreover, this impact will also help decrease the extreme value that society places on independence, which ignores and harms people who experience inevitable dependency throughout their lifetime.

Due to the inevitable nature of dependency, creating a pathway for dependency relationships to succeed benefits every member of society. It is likely that all individuals will serve as both a carer and a charge during different periods of their life. While not all of these situations will require a carer to take Paid Family Leave to care for a charge, by creating a pathway for people to do so, thousands of people who will inevitably find themselves in the position of being a carer or charge will benefit from PFL. Because an individual can never count on not being in the position of a carer or charge at some point in their life, it is in the best interest of all individuals to create an equitable path for those in dependency relationships to take that benefits both the charge and the carer.

Because the work of a carer is disproportionately allocated to women and minorities, implementing paid family leave will have a positive impact on reducing the power inequalities women and minorities currently experience. By providing carers with a mechanism to receive pay for their work as a carer, work that usually goes unnoticed and unpaid, PFL is helping provide financial and job security to women and minorities. Instead of not being able to take a job or having to quit a job to care for a loved one, carers can instead take paid family leave and receive compensation and job security, as well as recognition of their role as a carer, while they care for a loved one. This helps increase the financial success of carers, which decreases the likelihood of a carer being in an unhealthy dependency relationship. For instance, without PFL a woman in an abusive relationship who is unofficially tasked with caring for her sick child, which puts her in a situation where she could no longer keep her job, has no options to leave the abusive relationship. In this scenario the woman is financially dependent on her abuser and cannot obtain her financial independence without leaving her child deprived of needed care. However, if PFL was implemented, the woman would not have had to quit her job and could

have taken Paid Family Leave and received a stable income to help her achieve financial independence from her abuser, while also providing the care her child needs.

Providing financial compensation for the work of carers also helps contribute to a societal realization of the value of dependency work. Currently, the work of unofficial carers, those who are in a position to care for someone but are not professionally hired to do so, is often overlooked and not considered ‘work’ because no paycheck is associated with the labor. However, the effort, time, skill, and commitment that is required of effective carers can have an overwhelming impact on carers. As such, depending on the amount of care needed and its longevity, this role includes an obligation that is comparable to or exceeds what is expected of employees in the workforce. By providing compensation for carers who are supporting a loved one, society is recognizing the work of carers and the commitment that is required to be an effective carer. While even with the implementation of PFL, much of the dependency work that is disproportionately allocated to women and minorities will still go unrecognized and uncompensated, implementing PFL is the start to recognizing the role and importance of such labor in our society.

Paid Family Leave programs typically do not specify the gender of the person who is eligible to take leave, except in cases where the leave is being taken as a result of childbirth; thus, PFL helps reduce the impact of harmful gender roles. If PFL were implemented, both women and men could take leave after the arrival of a new baby, either from birth, adoption, or fostering, instead of the leave only being available to the woman. As a result, men could become more involved in work as a carer that is stereotypically assigned to woman. Instead of the wife of a stereotypical nuclear family leaving her job to care for a sick family member, PFL makes it possible for anyone, woman or man, to take paid leave. This allows for a more equal distribution

of work among women and men and creates an environment where the next generation can view this distribution of labor and have less affinity to negative gender stereotypes.

Misconceptions about Paid Family Leave

Despite the many positive impacts that are associated with Paid Family Leave, there are numerous popular misconceptions about the policy that hinder its implementation. One of the largest misconceptions about PFL is that it is bad for businesses, specifically small businesses; however, this is not the case in the majority of instances. In fact, there are numerous different aspects of PFL that can have a positive impact on businesses. By providing a mechanism for employees to remain a part of the workforce while taking leave to care for a loved one, or because they themselves need care, PFL increases worker retention instead of forcing workers to quit their job. This helps minimize the impact of having to hire, train, and integrate new workers and other turnover costs, which are estimated to average roughly 1/5 of an employee's annual salary.¹⁵⁶ By creating a work environment where dependency relationships and the obligations and needs that are associated with those relationships is recognized, employees are more likely to be productive and happy with their work experience.¹⁵⁷ Without PFL, many workers encounter stress, health problems, and commitments to those with health problems, that hinder their ability to be productive in a work environment and contribute to the employee having a negative conception of their job. The impact that PFL has on businesses can already be determined by analyzing the impact that the policy has had on states who have already enacted PFL. PFL has been implemented in California since 2004 and since its implementation 87% of businesses reported no increased costs as a result of the policy, and some businesses even reported cost

¹⁵⁶ CT Campaign for Paid Family Leave, CWEALF.

¹⁵⁷ CT Campaign for Paid Family Leave, CWEALF.

savings as a result of paid family leave.¹⁵⁸ It is because of these results and the many other numerous positive impacts from PFL that the vast majority of small businesses were in favor and actively campaigned for the implementation of Paid Family Leave in Connecticut.¹⁵⁹

Another misconception about Paid Family Leave is that it is unneeded because workers are already provided with enough leave by their employers. However, the majority of workers do not receive enough time off to address medical issues of their own or others. Even if workers can qualify for time off either because of their employers' policies or by participating in the federal FMLA program, this leave is often unpaid and does not meet the needs of the caregiver or the carer. Despite misconceptions, "currently just 17% of workers have access to paid family leave through their employer. Among low-wage workers, who are disproportionately people of color, that number falls to just 5%."¹⁶⁰ Moreover, there is no guarantee that individuals who are included in the percentage of those with access to paid family leave have the ability to take the necessary amount of time to care for someone else or themselves. It is also possible that the paid leave program provided by the employer is too narrowed in its application, rendering its impact null for those who do not meet the program's specific parameters.

Even out of those who support paid family leave, some individuals believe this policy should be enacted on a state level and should not be a national policy. However, only nine states and Washington D.C. have implemented Paid Family Leave policies or are currently working on implementing PFL. States are not implementing PFL in a timely manner which results in thousands of Americans not getting the care they need or encountering financial hardship as they strive to provide care for their loved ones without government assistance. A national PFL policy

¹⁵⁸ CT Campaign for Paid Family Leave, CWEALF.

¹⁵⁹ CT Campaign for Paid Family Leave, CWEALF.

¹⁶⁰ CT Campaign for Paid Family Leave, CWEALF.

would streamline and expedite this process to meet the need that state policies and the federal FMLA program is not adequately addressing.

While PFL may be perceived as a liberal policy with little hope of passing in the national legislature, PFL benefits all individuals, not just members of one political party. Everyone will encounter inevitable dependency throughout their lives and will likely be in a position to care for another who is dependent on them. A national PFL program would allow every American citizen the ability to respond to their own dependency or the dependency of another in a manner which respects the needs of both the charge and the carer. This provides Americans with the ability to maintain their own financial security and independence without relying on government assistance programs, thus mitigating any negative monetary ramifications to implementing PFL and increasing the productivity and happiness of the American people.

Political Considerations

When considering whether or not a public policy should be enacted, especially at the federal level, it is important to determine how much public support the policy has. Luckily, as Paid Family Leave has gone in and out of the public focus over the last ten years, polls and data regarding public support for PFL has already been collected and analyzed in recent years. In a comprehensive set of polls conducted and analyzed in 2016-17, the Pew Research Center came to the conclusion that there is a great deal of public support for PFL programs. According to this poll, 85% of Americans think that workers should be entitled to take PFL to address their own medical needs, 82% believe that mothers and 69% believe that fathers should be able to take PFL following the birth or adoption of a child, and 67% believe that workers should be able to take

PFL to care for a family member.¹⁶¹ As such, even though PFL programs receive the most support from members of the Democratic Party, it is clear that PFL receives bipartisan support, with roughly 75% of polled Republicans and Independents stating that they are supportive of paid medical and maternity leave.¹⁶²

It is also important to consider matters of equity when determining if and how a policy should be enacted. For instance, whether or not a policy is equitable could make the difference on if that policy passes or not. To some, the equitable nature of a policy could be the reason for voting in favor of the policy. For others, if a policy is equitable, it may not serve their desired purposes or benefit the constituency that a politician represents; thus, the equitable nature of a policy could result in its failure. As such, to help ensure the success of a policy such as Paid Family Leave, it is necessary to consider how matters of equity impact the policy.

In her book *Policy Paradox* Deborah Stone discusses some of the considerations that come into play when trying to create and implement an equitable policy.¹⁶³ Unfortunately, the solution to many problems cannot be completely and perfectly solved by public policy due to the wicked nature of the problem or lack of resources. Thus, one of the first considerations when trying to make an equitable policy is who should be the primary beneficiaries of the policy if only a finite number of people can be benefited. Stone points out numerous ways that this decision is made by policy makers. One of these strategies is based on membership, where certain people benefit from a policy because of their membership to a certain group.¹⁶⁴ For

¹⁶¹ Juliana Menasce Horowitz et al., “Americans Widely Support Paid Family and Medical Leave,” Pew Research Center’s Social & Demographic Trends Project (Pew Research Center, July 31, 2020), <https://www.pewresearch.org/social-trends/2017/03/23/americans-widely-support-paid-family-and-medical-leave-but-differ-over-specific-policies/>.

¹⁶² Horowitz Menasce Juliana et al., “Americans Widely Support Paid Family and Medical Leave.”

¹⁶³ Stone, Deborah A. *Policy Paradox: the Art of Political Decision Making*. New York City, NY: W.W. Norton & Co., 2012.

¹⁶⁴ Stone, Deborah A. *Policy Paradox: the Art of Political Decision Making*. (New York City, NY: W.W. Norton & Co., 2012), 42-45.

instance, people in the United States over the age of 65 qualify to receive Medicare simply because of their membership in a specific age group. Another way to determine how to equitably distribute the benefits of a policy is by merit.¹⁶⁵ One of the most common practices of this strategy is the allocation of academic scholarships, either due to academic or athletic merit. Others argue that equitable distribution is better achieved when it is based on rank because those of a higher rank deserve the benefits and may have a better use or allocation for the benefits.¹⁶⁶ A popular line of reasoning among advocates of liberal policies is that in order for a policy to be equitable, it must distribute based on need. Thus, a family under the poverty line has more need than a middle-class family and should receive more benefits from policies than the middle-class family.¹⁶⁷

In the case of Paid Family Leave, from the analysis provided by Eva Kittay, it is clear that there is a broad need for PFL to address the needs of dependency relationships. However, if only a relatively small group of people can be affected by the policy, the most equitable way to distribute the benefits of the policy must be determined. Luckily, thanks to polling that has been completed, this question can already be answered. While all Americans would benefit from the enactment of PFL, those in lower economic brackets have the greatest need for such a policy. Only roughly 6% of low-wage workers have access to PFL programs and the majority of those who do not have access PFL are unable to take unpaid leave for financial reasons or risk of losing their job.¹⁶⁸ Moreover, low-wage earners who can take family or personal medical leave,

¹⁶⁵ Stone, Deborah A. *Policy Paradox: the Art of Political Decision Making*. (New York City, NY: W.W. Norton & Co., 2012), 45-48.

¹⁶⁶ Stone, Deborah A. *Policy Paradox: the Art of Political Decision Making*. (New York City, NY: W.W. Norton & Co., 2012), 48-50.

¹⁶⁷ Stone, Deborah A. *Policy Paradox: the Art of Political Decision Making*. (New York City, NY: W.W. Norton & Co., 2012), 52-53.

¹⁶⁸ CWEALF, CT Campaign for Paid Family Leave.

either paid or unpaid, endure an incredible amount of hardship to do so. According to Pew Research Center, out of households that took leave and make less than 30k annually, 57% took on debt, 37% cut their leave time short, 46% put off paying bills, and 48% went on public assistance, all as a result of not receiving enough support while taking family or personal medical leave.¹⁶⁹ While populations with higher income levels still endure hardships while taking leave due to the lack of support provided, the presence and severity of the hardships decreases as household income increases. As such, if only a select group of people can receive the benefits from a PFL plan, those in low socio-economic brackets have the greatest need for such a program and should receive the highest priority if the policy is to be considered equitable.

Wicked Problems and Paid Family Leave

The need for paid family leave stems from wicked problems that have been left unaddressed in the United States. While wicked problems typically cannot be ‘solved’, if they are continuously addressed by society the salience and impact of the wicked problem can significantly decrease. Unfortunately, this has not been the case with the wicked problems that have caused the need for paid family leave. Due to the cyclical nature of wicked problems, there are many wicked problems that relate to paid family leave. For instance, failing to acknowledge inevitable dependency, assumed gender roles, inadequate healthcare, and the symptoms of capitalism are all wicked problems that can be linked to the need for paid family leave. Thus, when developing a political policy to address paid family leave, it is important to consider the related wicked problems throughout the planning process.

¹⁶⁹ Horowitz Menasce Juliana et al., “Americans Widely Support Paid Family and Medical Leave.”

One of the wicked problems that is most relevant to paid family leave is the societal problem of failing to acknowledge inevitable dependency. As described by Kittay, experiencing dependency throughout the human lifetime is inevitable. All humans are dependent on another throughout infancy and childhood, in illness and injury, and when they are elderly. As such, rather than overvaluing independency, as society currently does, it is in everyone's benefit if society instead acknowledges the inevitable nature of dependency and responds to dependency in a just manner.

Unfortunately, the inevitable nature of dependency has not been addressed within the United States. Instead, a high value is placed on independence and states of dependency are hidden and ignored. Workers are constantly forced to choose between caring for a loved one, or themselves, in a dependent state or maintaining their job and stability. For instance, mothers have no option other than to return to work before they are ready after birth, risking their physical and psychological health. The examples of the needs of people experiencing dependency being ignored in the United States are seemingly endless.

If the inevitable nature of dependency was acknowledged and properly addressed, the prevalence of the issues listed above would significantly decrease. This is because with a social understanding of the inevitable nature of dependency also comes the push for political policies that address dependency. As such, policies such as PFL and similar policies would be enacted to help decrease the salience of the wicked problem of inevitable dependency. Moreover, an increased social awareness of dependency would also increase the level of understanding and compassion that society would have towards individuals experiencing dependency. As a result, the social stigma against dependency would lessen and individuals experiencing dependency would be less ostracized by society.

While failing to address inevitable dependency may appear to be different than many other wicked problems, such as poverty, and therefore should not be classified as a wicked problem, this is not the case; in fact, the failure to respond to inevitable dependency meets all ten of the requirements of wicked problems that are specified by Rittel and Weber. Inevitable dependency is a socially complex problem that has no clear root, resolution process, or end. Moreover, there is no perfect way to resolve inevitable dependency, as it is an essential part of humanity with no 'true or false' answer. Responding to inevitable dependency is also an incredibly high-stakes game where human lives are at stake and there is no opportunity to test a response without significantly altering the lives of those who experience dependency. Inevitable dependency is also an incredibly distinctive wicked problem that is unique both in general and because each case of inevitable dependency differs and has different needs. Lastly, explanations of inevitable dependency can vary incredibly, further complicating the wicked problem and increasing the difficult task assigned to policy makers addressing inevitable dependency. Depending on how it is perceived, dependency can occur because of its inevitable nature as described by Kittay, inadequate health and nutrition, disability, a perceived weakness in an individual, or simply because someone complaining too much. The vastly different perceptions as to why dependency occurs also complicates discussions regarding how, and if, society and governments should respond to dependency. These qualities and more clearly categorize inevitable dependency as a wicked problem.

Given the wicked nature of inevitable dependency, solutions seeking to decrease the salience of inevitable dependency must be aware of the wicked nature of this problem. Solutions cannot be made with the expectation that all negative ramifications of inevitable dependency will be eliminated. Moreover, inevitable dependency is experienced by all humans and in the present

society can have incredibly negative implications; thus, inevitable dependency also cannot be left unaddressed despite the complicated and unsolvable nature of the problem. As such, political policies that decrease the salience of inevitable dependency, while bearing in mind the complicated nature of the problem, must be enacted. Paid family leave answers this call.

The enactment of paid family leave would not solve inevitable dependency; however, it would decrease the salience and impact of the current negative ramifications of inevitable dependency. One of the main benefits of PFL is that it creates a general policy that can then be catered to meet the needs of each case of inevitable dependency, thus properly responding to the unique nature of this wicked problem. Because PFL does not put stipulations on how care is to be administered to those experiencing dependency, has different lengths to correspond to the severity of the state of dependency, and allows family members and loved ones who know each other best to care for those in need, PFL can be customized to the needs of each case without complicating the general policy. PFL also increases the financial status and job security of individuals who experience dependency or who must care for someone who is dependent on them. Lastly, PFL helps combat the wicked problem of inevitable dependency on a social level by slowly normalizing dependency and how to ethically respond to states of dependency. Thus, while PFL is not a ‘perfect’ solution to inevitable dependency, the enactment of Paid Family Leave would significantly decrease the amount of negative impacts that society experiences due to this wicked problem.

Recommendation

Paid Family Leave programs respect the humanity of employees and the role that the need to give or receive care plays in many people’s lives. PFL provides individuals and families

with financial and job security, higher quality care, and decreases the amount of stress that is put on employees during trying times when they themselves need care or they need to provide care for their loved ones. As I stated in my testimony given in support of Paid Family Leave in Connecticut, “Without paid family and medical leave, workers are often forced to choose between financial security and caring for a loved one in a time of great need. Financial security is a necessity: workers should not be stressed about their ability to pay bills and provide food for their family while also caring for a family member. This is an unfair and unethical decision”.¹⁷⁰ It is for these reasons that I recommend the implementation of a national Paid Family Leave policy.

Enacting Paid Family Leave on a national level recognizes the presence of inevitable dependency in the lives of every American citizen and the responsibility that thousands of Americans have to care for their loved ones, at the cost of their own finances and time. Currently those in need are not able to receive care because they cannot take time off of work themselves or a loved one cannot take time off to provide care for them. When carers do take time off of work to provide care for someone, they are forced to do so with the risk of losing their job, encountering financial hardship, and an increased likelihood that they will have to become reliant on government assistance programs to meet their daily needs. Not only does PFL provide a mechanism for carers to receive support and relief and for charges to get the care they deserve, but PFL would also start paving the path for societal change that follows the ideals represented in the concept of *doulia* proposed by Eva Kittay.

Countless citizens are forced to make impossible decisions when they have to choose between either maintaining their job or caring for a loved one, and many never have the

¹⁷⁰ Gibson, Piper, “Our State’s Future Depends on Paid Leave,” CT Campaign for Paid Family Leave, Sep 32, 2019.

opportunity to make this choice. Consider the case of Danielle in Connecticut, “after just starting at a new job, Danielle had not worked enough hours to be eligible for FMLA’s job protected leave when her father entered hospice care. Faced with limited choices, Danielle spent the last few hours of her father’s life working remotely from his bedside”.¹⁷¹ This is an immoral decision to force Americans to make when national legislators have the power to create a solution that respects the needs of the American people.

¹⁷¹ Granato, Madeline, “Twenty-Six Years after FMLA, Paid Leave is Coming to CT,” The CT Mirror, Aug 5, 2019.

Chapter 5: The Community Choice Act

Introduction to the Community Choice Act

Under the current status quo, individuals who receive Medicaid and need an extensive amount of care do not have the ability to choose how and where they receive their care if they hope to have the cost of their care subsidized by Medicaid funds. Instead, they are forced to receive care in an institution, such as a nursing home, which often means the individual has to sell all significant assets, including their home, and sacrifice their agency. This infringes upon the rights of the charge and decreases the likelihood that they will receive the personalized care they need. However, if passed, the Community Choice Act (CCA) would require that “every Medicaid eligible person with disabilities, as well as older Americans, have the choice between receiving care in their homes or in an institution”.¹⁷² As a result, not only would the undesirable practice of forcing individuals to sell assets that are important to them be stopped, but those in need of care would be able to choose the manner of care that best fits their needs, respecting the needs and autonomy of the charge. Moreover, the current policy is discriminatory against those who cannot afford to fully pay for their own private care by themselves, while those who can afford to pay for their care are not limited as to whether or not they receive their care at home or at a care institution. The Community Choice Act protects the autonomy of people in long-term states of dependency, while also decreasing the social stigma against dependency which is experienced by many individuals, but not witnessed by society because such individuals are removed from the community and placed into an institution. While enacting this plan does come at a cost, the benefits and effectiveness of the Community Choice Act actually render the

¹⁷² Disabled World, “Health Care Reform, The Community Choice Act, and People with Disabilities,” Disabled World, June 29, 2010. <http://www.disabled-world.com/disability/awareness/community-choice-act-disability.php>.

implementation of the CCA economically advantageous. Some may believe that such a policy should be decided and implemented on a state and not a national level. However, for the disabled and elderly population to have their autonomy protected and receive the quality and choice of care they are entitled to, the Community Choice Act should be passed by the Congress of the United States of America.

Olmstead v L.C.

The legal precedent for amending the approved use of Medicaid funds to include private and community-based care instead of merely institutional care stems from the 1999 United States Supreme Court case *Olmstead v L.C.*¹⁷³ In this case, two women with mental illness and developmental disabilities were voluntarily admitted to a regional hospital. After receiving treatment, the two women were then approved to move their care from the institution to a community-based program; however, they were not released from the hospital until several years later, after the women filed for release under the Americans with Disabilities Act (ADA).¹⁷⁴ The case then made it to the US Supreme Court where it was decided that “unjustified segregation of persons with disabilities constitutes discrimination in violation of title II of the Americans with Disabilities Act;” as such, public entities have the responsibility to provide private care to those with long-term disabilities when it is possible to do so.¹⁷⁵ By specifying the ‘unjustified segregation’ of disabled people, specifically by forcing them to either enter or remain in an institution of care, the main legal precedent for the CCA is established. Under the current status quo, forcing those with a disability who do not have the funds to independently pay for, but

¹⁷³ ADA, “Olmstead: Community Integration for Everyone,” ADA, Accessed January 11, 2021, http://www.ada.gov/olmstead/olmstead_about.htm.

¹⁷⁴ ADA, “Olmstead: Community Integration for Everyone.”

¹⁷⁵ ADA, “Olmstead: Community Integration for Everyone.”

require extensive care, into a care facility is a form of segregating people who experience dependency. Moreover, because those who are receiving care from Medicaid funds do not have the ability to pay for care themselves, there is no other option for disabled people to get the care they need to survive and thrive; thus, they are segregated into a care institution and all other care options are not available to them.

In the explanation of the majority decision, the Supreme Court states that the ruling reflected two judgements which also furthers the legal precedent for the enactment of the CCA. The first justification is that care that is not confined to an institution can help diminish the prevalence of negative stereotypes related to disability. The CCA supports this judgement by providing disabled and elderly people the ability to receive care within their own homes and community; thus, the stereotype that disabled people should not be a part of society will be lessened because disabled people will become more integrated into society and local communities.

The second judgement in the *Olmstead* majority opinion is that institutional care diminishes the “everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment”.¹⁷⁶ Implementing the CCA would solve this problem by providing disabled people with an option to receive the care they need outside of an institution and instead receive care in an environment where they can maintain family and community relationships as well as many other forms of personal advancement, including educational and vocational opportunities.

¹⁷⁶ ADA, “Olmstead: Community Integration for Everyone.”

Current Implementations of the CCA at a State Level

There are two main examples of programs that have been enacted at the state level that are comparable to the Community Choice Act. The first is the Nursing Home Transition Demonstration Program which operated between 1998 and 2000 and awarded grants to 12 states to help assist those in nursing homes who wished to move back into their community.¹⁷⁷ While this program did not specifically reallocate the use of Medicare funds, it serves as an example of how the use of government funds can have a positive impact when allocated to supporting community-based rather than institutional care. A project report on the Nursing Home Transition Demonstration Program in New Jersey found that the biggest barriers to enacting such a plan was not the cost or ineffectiveness of the program, but resistance to or lack of knowledge about community-based or private care options from the staff at nursing homes.¹⁷⁸ During this program, in New Jersey alone 3,400 people left nursing homes and entered into community-based or private care programs, 1,600 of those were on Medicaid.¹⁷⁹ In an evaluation of the program after it was completed, 86% of those who left an institutionalized care facility reported being happier with their current living situation in comparison to their living situation at a care facility.¹⁸⁰ As a result of this program, New Jersey “authorized \$4 million in State Fiscal Year 2002 for Medicaid HCBS waiver services specifically for former nursing home residents under the age 65” to provide more individuals in institutionalized care facilities with the option of switching to community-based or private care.¹⁸¹

¹⁷⁷ Steve Eiken, “Community Choice: New Jersey’s Nursing Home Transition Program,” ASPE, US Department of Health and Human Services, Feb 17, 2017. <https://aspe.hhs.gov/basic-report/community-choice-new-jerseys-nursing-home-transition-program>.

¹⁷⁸ Eiken, “Community Choice: New Jersey’s Nursing Home Transition Program.”

¹⁷⁹ Eiken, “Community Choice: New Jersey’s Nursing Home Transition Program.”

¹⁸⁰ Eiken, “Community Choice: New Jersey’s Nursing Home Transition Program.”

¹⁸¹ Eiken, “Community Choice: New Jersey’s Nursing Home Transition Program.”

The second example of a program on a state level that is comparable to the Community Choice Act is the Community First Choice (CFC) which “allows States to provide home and community-based attendant services and supports to eligible Medicaid enrollees under their State Plan” on an opt-in basis where state governments must opt-in to the program for it to be made available to the residents of the state.¹⁸² Although the CFC is not supported by many disability rights groups due to its opt-in conditions which significantly decrease the impact of the CFC, the Obama administration passed the CFC in 2009 as part of the Affordable Care Act.¹⁸³ The refusal of the Obama administration to support the CCA and instead pass the CFC, contrary to previous promises the President made to disability rights groups, led to protests in Washington D.C. and the arrest of over 90 supporters of the CCA who were protesting outside of the White House.¹⁸⁴ The CFC is currently only available in seven states, California, Montana, Maryland, Connecticut, Texas, Washington, and Oregon.¹⁸⁵ In a report to the US Congress, it was noted that participants in this program reported higher levels of independence, increased involvement in their communities, increased productivity, and higher quality and more personalized care.¹⁸⁶ However, due to the limited application of the CFC, further legislation is needed to provide those who experience dependency with the autonomy to choose the parameters of their own care, no matter what state they live in.

¹⁸² Sylvia Mathews Burwell, “Community First Choice: Final Report to Congress,” Community First Choice (CFC) 1915 (k), Medicaid, December 2015, <https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/community-first-choice-cfc-1915-k/index.html>.

¹⁸³ “Community Choice Act National Kickoff Draws Thousands,” ADAPT, ADAWatch, March 24, 2009, <https://adapt.org/wp-content/uploads/2009/10/Incitement-2009-Volume-22-no.8.pdf>.

¹⁸⁴ “Community Choice Act National Kickoff Draws Thousands,” ADAPT.

¹⁸⁵ Burwell, Community First Choice: Final Report to Congress.”

¹⁸⁶ Burwell, Community First Choice: Final Report to Congress,” 33-34.

Benefits of the Community Choice Act

There are numerous different benefits that would result from the passage of the Community Choice Act. These benefits can be divided into three different categories: benefits for the charge, carers, and society. Charge's who are in a state of dependency, such as the disabled and elderly population, would experience benefits from the CCA regarding an improvement of the quality of their care and the protection of their rights. Carers would experience benefits related to an increased demand for carers and a better distribution of dependency workers, relieving stress on overworked carers at care institutions. Lastly, society will experience benefits as the social stigma against dependency is reduced and communities and families are brought together:

People who are currently experiencing dependency have a vested interest in the passage of the CCA because the program would specifically address the parameters of the care they can receive and their ability to exercise their personal autonomy and choose the manner of their care. This affects both individuals who are currently in a care institution and those who are not. Those who are currently in a care institution have an interest in the CCA because such a policy provides them with another manner in which they can receive the care they need other than receiving care in an institution, which might not provide the manner of care that is most advantageous to them. Those who are not in a care institution but who experience dependency also have a vested interest in the enactment of the policy because the CCA may prevent them from ever having to enter a care institution if they do not want to. Additionally, the CCA could provide intermediary levels of care to those who still need personal care, but not to the extent that it is necessary for them to live in a care institution. Under the same reasoning, all individuals have a vested interest in the CCA. Every human will inevitably experience dependency throughout their lifetime, either

due to illness, disability, old age, or other various causes. Thus, every human has a stake in the enactment of the CCA both for their own interests and for the sake of every person they know who is currently experiencing dependency.

One of the largest benefits to those who experience dependency is the increase in the quality of care that would be possible if the CCA was enacted. Eva Kittay argues for personalized care that helps meet the individual charges needs in a manner that acknowledges the charges state of dependency and seeks to provide the care that best respects the charge and provides them with the support they need to flourish. Such a level of highly personalized care is difficult to achieve in a care facility where care is administered to a large amount of people based on what is best for the group of people as a whole, not necessarily what care is best for each individual within the care facility. However, if care is administered by personal carers or within a smaller community that has the ability to provide highly personalized care, the quality and variety of care that can be provided to charges will increase.

The personalization of care that could occur if the Community Choice Act were to be passed would help meet the genuine needs and legitimate wants of the charge, something that is hard to achieve when care is not individualized.¹⁸⁷ Eva Kittay uses the experiences of her own daughter Sesha to articulate the difference between needs and wants. A caregiver that meets Sesha's genuine needs of cleanliness, nutrition, help with movement, etc. is meeting Sesha's genuine needs. Someone turning music on or singing to her is meeting Sesha's legitimate wants, something that her body could live without to survive but is necessary for her to live a flourishing life. Both of these categories of care are necessary for an individual to thrive; however, meeting these needs is almost impossible in a care institution and is much better met

¹⁸⁷ Kittay, *Learning from My Daughter*, 178.

when care can be given on a personal basis within a community. For instance, for an individual who uses a wheelchair, a genuine need could be assistance with cooking meals and running various different errands; however, this does not mean that the individual requires care in an institution. Instead, the individual could have a personal carer who could provide prepared meals and complete various different tasks so that the charge can live an independent life in a manner that still accounts for their dependency. Furthermore, a legitimate want of the charge could be attending various different family gatherings. Such an opportunity is difficult to achieve when the charge is admitted to a care facility; however, if the charge receives their care from home, a personal carer could help transport the charge to the gathering and provide care while at the gathering, such as assistance with using the bathroom, in a manner that does not take away from the charges experience with their family. In this scenario, which would be made possible by the CCA, disabled and elderly people can have their genuine needs met by care that is tailored to their individual needs. They can also have their legitimate wants met at a higher rate and, as they are not being removed from society and placed into a care institution, it is likely that they will be able to maintain more inter-personal relationships with members of their family and community.

Eva Kittay argues that respect is an essential part of proper care in order to avoid paternalism when providing care.¹⁸⁸ While some may argue that paternalism is simply a side-effect of care that cannot or should not be avoided, paternalistic care disrespects the charge. When care is performed in a paternalistic manner, the desires and wishes of the charge are not properly considered. Additionally, the charge is disrespected and not considered someone who has the ability or right to make decisions regarding their own personal autonomy. While there are some situations where care is provided for charges who are not fully autonomous or cannot make

¹⁸⁸ Kittay, *Learning from My Daughter*, 208.

some decisions for themselves, this does not mean that the care provided for them must be inherently paternalistic. Instead, Kittay argues that in such situations, or when the carer believes the charges wishes could be harmful, that the carer should address the charge's "genuine needs and legitimate wants as she [the charge] does (or would) understand them, even if she herself does not yet acknowledge these."¹⁸⁹

For instance, if a carer knows the charges preferred foods and the carer serves the charge food they like, even if the charge does not have the ability at the time to convey their desire as to the food they want to eat, the carer is respecting the charges autonomy and opinion even when the charge cannot express it. If instead the carer knowingly chose to serve the charge food they did not like, but the charge had no ability to protest, even if the food had the same beneficial impact on the charge's health, the carer is acting paternalistically and not respecting the charge's autonomy. While this may appear to be a simplistic example, maintaining personal autonomy and the ability to make decisions about your life is a meaningful aspect of humanity that must be preserved when possible.

To avoid paternalism and respect the desires of the charge, personalized care should be administered by those who have a connection with the charge. Such care is hard to achieve in caring facilities where staff oversee a large number of people and have limited care options. However, if the CCA was passed and more community and home-based care was provided, charges would have a greater likelihood of receiving personalized care that respects their autonomy and is catered towards their desires and opinions. Moreover, simply by enacting the CCA and providing more options as to how a charge can receive care, the autonomy and ability for a charge to choose the manner of their own care is increased. Under the current status quo, if

¹⁸⁹ Kittay, *Learning from My Daughter*, 210.

an individual is in need of significant care and cannot afford a private carer themselves, their only option to receive care is to enter a care facility, such as a nursing home. This forces those who experience dependency to significantly alter their life in a manner which they may not desire; however, the CCA solves this issue and would provide thousands of people who experience long-term dependency with a variety of different care options.

Another benefit of the Community Choice Act which increases the autonomy and likelihood that the legitimate wants of those receiving care will be fulfilled, is the ability for charges to remain integrated within society while receiving care. Under the current system, those who experience long-term dependency are essentially removed from society and placed into a care facility. This removes the charge from various different opportunities and experiences which lead to a fulfilling life. When someone is in a care facility it is harder for them to receive an education, obtain a job, socialize, and participate in their community and family. Not only does this have a negative impact on the fulfillment of the legitimate wants a charge may have, but it could also have long-term impacts on the charge. If the charge is placed into a care facility it can be incredibly hard for the charge to then return back to society and find a job or continue their education, even if their state of dependency was only temporary. Not only can this have a lasting impact on the charge's ability to flourish in life, but by making it more difficult for those who experience dependency to reintegrate into the workforce or obtain an education, the social stigma against dependency is reinforced. However, if the charge remains integrated within society in their own home it is easier for the charge to continue to be an active part of their community. For instance, while receiving care in their home, a charge could take online classes, work remotely, or even attend work or school in-person on a part-time basis. These options are not possible for individuals in a care facility. Additionally, due to their removal from society, a

charge may feel disconnected from friends and family. This removal can have a significant impact on the charge's relationships and mental health. However, under the CCA those who need long-term care can receive the care they need within their community and still maintain meaningful connections with friends and family.

People who work in the field of medical care also have a vested interest in the passage of the CCA. To those who provide private or community-based care, the enactment of the CCA would likely significantly increase the demand for such care. Moreover, for those who currently work at a care institution, the enactment of the CCA could have both positive and negative implications on their employment. The CCA could help mitigate some of the stress placed on workers at institutions of care because the worker to patient ratio may be improved in a manner which reduces the demand on care workers. Secondly, if the CCA has a significant impact on the number of people who receive care from care institutions, the employment of care workers at such institutions could be threatened. However, this scenario is unlikely because care institutions typically operate at max capacity and have a waiting list of patients who would like to receive care when space at the institution is available; thus, even if the number of people who attend care institutions decreases, due to the current extreme demand for services at care institutions, it is unlikely that the CCA would pose a significant threat to the employment of those who work at institutions of care.

Taxpayers also have a stake in the CCA if its enactment would come at a large cost that would result in the increase of taxes; however, this is not the case. The average annual cost of care at an institution is roughly \$75,000, while community-based services cost roughly \$23,000 annually.¹⁹⁰ In Texas, where a plan similar to the CCA was enacted and 18,000 people moved

¹⁹⁰ Jennifer LaFleur, "Nursing Homes Get Old for Many with Disabilities," ProPublica, June 21, 2009. <http://www.propublica.org/article/nursing-homes-get-old-for-many-with-disabilities-621>.

from nursing homes to community-based care programs from 2001 to 2009, costs did not rise.¹⁹¹ As such, Medicaid dollars could potentially help three times the amount of people if they were used to pay for community-based care rather than institutional care. While there may be an upfront cost of the CCA that is associated with creating the new policies needed for the CCA to be successfully enacted and expanding current policies, it is unlikely that the initial cost of the implementation of the CCA would create a significant tax burden.

Not only would the Community Choice Act not pose a significant tax burden on Americans, but it is also supported by the general population. After a brief explanation of the policy, when asked if they support the CCA 66% percent of polled Americans expressed their support.¹⁹² Furthermore, when asked if they would support the CCA if it was associated with a \$6 average increase in their annual taxes, a cost that was initially projected by some analysts, 89% of polled Americans supported the CCA.¹⁹³ Thus, the American people recognize the need for the CCA and support its implementation, even if there is an associated cost which they would have to pay.

The American society would also benefit if the Community Choice Act was enacted because the societal stigma against disabled and elderly people who are in a state of dependency would decrease. Currently, many people who are in a state of significant dependency are removed from society and placed into an institution of care. This practice results in the ‘otherization’ of the disabled and elderly population and supports the stigma against them. However, if more disabled and elderly people who experience dependency were integrated into society, communities would begin to realize that those who experience long-term dependency

¹⁹¹ Lafleur, “Nursing Homes Get Old for Many with Disabilities.”

¹⁹² Michelle Diament, “Poll Shows Public Support for Community Living,” Disability Scoop, May 24 2010 <http://www.disabilityscoop.com/2010/04/28/poll-community-living-act/7854/>.

¹⁹³ Diament, “Poll Shows Public Support for Community Living.”

should still be valued members of communities and society. If disabled and elderly people were more integrated into communities instead of removed from them, they would have greater employment and educational opportunities that would increase their presence in communities, as well as their ability to form relationships with other community members. As such, society would begin to reduce the otherization of disabled and elderly people as they personally witness the positive ramifications associated with accepting disabled and elderly people within society.

Political Considerations

Two of the biggest political considerations to contemplate regarding the CCA is whether or not the Community Choice Act should be enacted on a state level or national level, and if it should be the role of the national government to pass welfare policies such as the CCA. While under the CFC, enacted by President Obama, states have the ability to allow individuals to allocate Medicare funding to cover home and community-based care, this plan is not ideal. By leaving this decision to states, many people are not given the option of receiving their care outside of a care institution if their state does not offer CFC. 43 states currently do not offer CFC to their residents, leaving thousands of disabled and elderly people with diminished personal agency and little to no options as to how they receive their care.¹⁹⁴ Simply from a moral standpoint, the quality of care someone receives and the amount of self-advocacy and control over their own life should not be dependent on what state they live in. Moreover, many of the issues with the CFC that were cited in the report presented to Congress could be solved with the national implementation of the CCA. States cited difficulty navigating a “patchwork” of programs and effectively communicating with the many different individuals and agencies that

¹⁹⁴ Burwell, Sylvia Mathews. “Community First Choice: Final Report to Congress.”

are involved with the CFC.¹⁹⁵ However, if the CCA was enacted on a national level, communication and agencies could be streamlined to make the process of using Medicare funds for community-based and private care easier to navigate for all those involved. Moreover, under current CFC policies, each state has different versions of the CFC that can change who is eligible, what services are provided, how much money is allocated, etc.. These differences can be very confusing for individuals who are considering the CFC when they are trying to determine what the CFC is, if they are eligible, and if it is a good option for them. Lastly, the enactment of the CCA on a national level would help increase the public awareness of community and private-based care options and the associated benefits. As a lack of knowledge was one of the major challenges cited with the promotion of the Nursing Home Transition Demonstration Program in New Jersey, increased knowledge and understanding about community-based care programs could significantly improve the public perception of the CCA and the likelihood that individuals would want to participate in the CCA.

While some may believe that it is not the national government's role to pass welfare policies such as the CCA, the CCA is merely the expansion of a current government program that responds to the needs of the people. The enactment of the CCA would not create more government welfare programs or drastically change the role that the government plays in the lives of American citizens, two aspects of many welfare policies that are often the most contested. Instead, the CCA expands the current welfare policy, Medicaid, that is already enacted on a federal level. This expansion does not expand the government's role, but instead gives American citizens more choice as to how they receive their care.

¹⁹⁵ Burwell, Sylvia Mathews. "Community First Choice: Final Report to Congress," 47.

Constraints and Challenges

While there are many benefits to enacting the Community Choice Act, there would also be some challenges, specifically relating to the initial implementation of the CCA. For instance, when considering how a public policy should be enacted, it is important to determine how much efficiency should be valued. While valuing efficiency may appear to be a positive attribute of a public policy, as discussed by Rittel and Weber in their theory on wicked problems, valuing efficiency blindly without considering the possible ramifications can have catastrophic results and lead to the increased salience of wicked problems. Thus, it is important to consider how matters of efficiency would impact the enactment of the Community Choice Act. While the ability to integrate the CCA into existing healthcare programs does make the enactment of the policy easier, it is important to acknowledge the specific needs of the CCA and not just incorporate the new policy into existing policies without considering how one might impact the other or the specific needs of each policy.

For example, to implement the CCA, Medicare and policies, programs, materials, etc., that relate to Medicare would have to be amended. For instance, new information on the CCA as an option for those on Medicare would have to be produced and old information would have to be amended. A comprehensive plan for the national enactment of the CCA would also have to be created, including deciding who would be eligible, how much Medicare funds would be allocated to each case and to the program in general, and other relevant decisions would have to be made. Furthermore, government workers and others involved in Medicare would have to be educated about the CCA so they understand the policy and could help those considering the CCA as an option for their care of the care of a loved one. This challenge does not come at a significant cost but would take time to complete and various stages of review to make sure all

needed changes were made. Luckily, the initial groundwork for the changes needed to implement the CCA has already been laid by the Community First Choice, creating a precedent that can be followed and expanded upon at a national level.

An increased demand for personal carers or community-based care programs could also pose a challenge if the CCA was enacted. If the enactment of the CCA results in a significant amount of people leaving institutions of care and turning to home or community-based care, those who provide such care could be initially overwhelmed. However, where there is an increase in demand for jobs, eventually the market recognizes this need and more people will apply for personal care jobs; moreover, those who work at a care institution could also change their position and become a personal carer. Thus, while the CCA may lead to short-term overwhelming demand for home and community-based carers, it is likely that this problem will naturally resolve itself. Furthermore, the creation of new job positions has a positive impact on the economy and the lives of many Americans who are looking for a job.

The Issue-Attention Cycle and the CCA

Analyzing the Community Choice Act is somewhat difficult given the lack of relevant literature and data that is available. However, the lack of information pertaining to the CCA is not a reflection of the importance of the problem; instead, it is a result of the CCA's progression through the issue-attention cycle. The CCA has already gone through all five stages of the issue-attention cycle and as a result has failed to regain the focus of the public eye. Thus, policy makers that hope to enact the CCA must reengage the public on this important issue to increase the media and academic attention that the policy receives. If the need for public support is not recognized, implementation efforts of the CCA are unlikely to succeed.

The first stage of the issue-attention cycle that the Community Choice Act was impacted by was the pre-problem stage. This stage occurred roughly prior to 2007, after which the CCA began to receive national attention; however, the need for the Community Choice Act has existed for decades prior. Prior to 2007 disability rights groups and other related organizations knew of the need for the CCA, and actively tried to gain public support for the policy; unfortunately, their efforts failed to gain much traction and only appealed to a select group of people who were personally impacted by the need for the CCA.¹⁹⁶ Individuals such as people in long-term care programs who did not want to live in a care institution, those who needed significant levels of care but not to the extent of care provided in a residential institution, family members of these individuals, and others personally felt the need for the CCA. However, because the CCA did not receive much attention from the media at this point, many potentially interested parties never learned about the policy.

The second stage of the issue-attention cycle, alarmed discovery and euphoric enthusiasm, occurred in 2007 when the Community Choice Act received national recognition. This recognition was finally achieved, when thanks to the efforts of disability rights groups, the CCA was presented and debated in the National Senate Finance Committee, who is tasked with hearing all bills that relate to Medicare or Medicaid before they reach the main floor of the senate.¹⁹⁷ The presentation of the CCA at the national level significantly increased public knowledge on the topic and also placed more pressure on media organizations to investigate and discuss the CCA. As a result, the CCA gained public support as more people learned about the policy, its benefits, and the need for the CCA in society. In response to the increase in public

¹⁹⁶ “Hundreds of Advocates Park the House for the CCA!”, Community Choice Act Action Hub, National Council on Independent Living, Jan 16, 2008. <https://web.archive.org/web/20090702131444/http://www.ncil.org/news/CCAActionHub.html>

¹⁹⁷ “Hundreds of Advocates Park the House for the CCA!”, Community Choice Act Action Hub.

support for the policy, many notable politicians actively expressed their support for the CCA. Those who supported the policy include, (then Senator) Barack Obama, (then Senator) Joseph Biden, Senator Tom Harkin, Senator Edward Kennedy, Senator Bernie Sanders, Senator Charles Schumer, and many other notable politicians.¹⁹⁸ Even (at that point in time) soon-to-be United States President Barack Obama, a co-signer of the bill, promised to pass the CCA if elected president, making it high on his priority list of healthcare improvements he advocated for.¹⁹⁹ In short, by mid-2007 the future for the enactment of the Community Choice Act finally looked bright.

Unfortunately, the traction the Community Choice Act gained in 2007 would gradually decrease as the CCA entered into the third and fourth stages of the issue-attention cycle. After failing to gain enough traction to pass in the 2007 legislative session, the CCA was sidelined as the country became more focused on the upcoming 2008 presidential election. In 2009 the CCA was reintroduced to the Senate; however, the CCA failed to make it past the introductory stages of the Senate hearing processes. At this point, many organizations and politicians began to pressure President Obama to include the CCA in his healthcare reforms as he had once promised.²⁰⁰ Likely fearing that the attempting to pass the CCA would draw too much attention, resources, and political capital, the Obama administration did not advocate for the enactment of the CCA. Instead, the Obama Administration created the Community First Choice policy as part of the Affordable Care Act, which instead of addressing and eliminating the need for the CCA, merely created a policy which drew attention away from the CCA. The passage of the CFC in combination with the ACA gave the illusion that the need for the CCA had been addressed, and

¹⁹⁸ Hundreds of Advocates Park the House for the CCA!”, Community Choice Act Action Hub.

¹⁹⁹ “Community Choice Act National Kickoff Draws Thousands .” ADAPT.

²⁰⁰ “Community Choice Act National Kickoff Draws Thousands .” ADAPT.

thus no longer needed to occupy the attention of the media or general public. As a result, the Community Choice Act became gradually forgotten by the general public and national politicians.

The Community Choice Act is currently in the last stage of the issue-attention cycle, the post-problem stage. At this point, due to the lack of national attention on this issue, organizations that still advocate for the CCA have instead focused their efforts on state legislatures to advocate for the CCA at the state level. While these actions have led to some progress in select states, the CCA has failed to gain any real traction since the passage of the ACA. However, the need for the CCA still remains as thousands of people who need long-term care are forced to live in an institutional care facility without their consent and are not receiving the quality of care they deserve and need. Thus, it is important that current politicians rekindle the fight for the CCA and increase public support for its enactment. While this may seem like a difficult task, thousands of Americans personally know someone in an institutional care facility, quite possibly someone who does not want to or need to be there. Thus, many Americans have a personal stake to the enactment of the CCA. However, many individuals still do not know there is an alternative option to institutionalized care facilities. As such, for the CCA to be passed, it is important that public awareness about the policy, and its associated benefits, increases and provides Americans with the knowledge that they can have choice in the type of care they receive.

Wicked Problems and the CCA

Like, PFL the need for the community choice act stems from wicked problems that have been left unaddressed. Wicked problems such as inevitable dependency, inadequate healthcare, undervaluing disabled and elderly lives, and impersonal healthcare practices have all led to a

world where the CCA is needed. Failure to properly address these wicked problems and reduce their salience has created social problems where the need for adequate healthcare is not appropriately prioritized or considered a human right, and many of the lives who need long-term care are not valued on the same level as those who are fortunate enough not to have to rely on such care. If the above wicked problems had been addressed and their negative ramifications lessened, health care would be more personalized and delivered to a greater amount of people at a higher quality; moreover, the lives of those who need long-term care and those who do not would be valued equally by society. If these changes had occurred it is possible that the CCA would already be in place or would not be needed due to more significant social change; however, because many wicked problems that relate to the CCA have been left largely untouched, the CCA must be enacted.

One wicked problem that relates most to the need for the Community Choice Act is the current lack of personalization in healthcare. Philosopher Eva Kittay learned the importance of personalized healthcare while caring for her disabled daughter Sesha. Sesha's needs are unique, she needs personalized care to ensure that she is not hurt throughout the caring process, that she receives nutritional food she cannot provide for herself, and that her unique combination of disabilities is monitored and addressed. Moreover, Sesha also needs someone to care for her legitimate wants, to sing for her, talk to her about her family, put music on she likes, and other actions that bring meaning and joy into Sesha's life. All this care must be provided on a highly personalized basis that respects Sesha's dignity and places value on the quality of life that she lives. Such care is hard to achieve in an institutional care facility. However, if a program such as the CCA was enacted and people like Sesha could receive highly personalized care within their own community at a reasonable price, the lives of those who receive long-term care would

significantly improve. Additionally, if a higher quality of care is given to those in need, it is likely that the health of some individuals will be improved insomuch that they will be able to transition out of long-term care programs.

Similar to inevitable dependency, the lack of personalization of many healthcare practices is not commonly considered a wicked problem; however, this social problem contains all the attributes and more that Rittel and Weber attribute to wicked problems. Increasing the personalization of healthcare is not a problem that has a clear step-by-step solution with a clear end; instead, policy makers who are addressing personalization in healthcare will be continuously forced to balance increasing the quality and personalization of care with increasing the quantity of individuals who can receive care. Moreover, care can always become more personalized, thus there is no ending point to this wicked problem. Additionally, because policies regarding healthcare can have life or death consequences, there is no room for error; furthermore, it is impossible to try out different healthcare policies without being prepared to expect all positive negative ramifications that could result from a failed policy.

The wicked problem of a lack of personalization in healthcare, specifically long-term health care, stems from society's failure to properly address numerous other wicked problems, such as: failing to address inevitable dependency, balancing government control with individual rights, the prevalence of poverty, and many other wicked problems. Lastly, the failure to provide personalized healthcare is an incredibly subjective issue and thus can be presented in many different ways. Some could argue that centralized healthcare programs and policies are efficient and benefit the greatest amount of people possible, others could say that the real problem is that the practices of modern medicine need to improve, while others such as Kittay would argue that

the need for personalized healthcare is great and would significantly improve the lives of many individuals in long-term care.

While enacting the Community Choice Act would not eliminate the wicked problem of a lack of personalization in healthcare, it would increase the personalization of care that many individuals in long-term care programs would receive while decreasing the salience of the wicked problem as a whole. The CCA would improve the personalization of care available to people who need long-term care in two main ways. By allowing individuals to choose whether or not they receive community-based care or care in an institution increases the level of choice that charges have to determine which method of care best meets their unique needs. Furthermore, by enacting community-based or one-on-one care, the care that is administered can be specifically tailored to meet the individualized needs of each charge. This is because the CCA, in contrast to most institutional care programs, significantly reduces the charge to carer ratio and allows carers to better meet the needs of the charge.

For the benefits of the CCA to come to fruition and the salience of the wicked problem of the lack of personalized care to be decreased, certain political considerations must be made. Solutions cannot be made with the expectation that all instances of people not receiving care that is personalized to their needs will be eliminated. Moreover, given the current expense of healthcare, for the good of the entire American population, the quantity, not merely the quality and level of personalization, of those who receive healthcare must be considered. That being said, as Kittay recounts in her experience with her daughter, having highly personalized care can make the difference between life and death and a life with meaning or a life without; thus, despite the associated cost, the level of personalization of healthcare cannot be left unaddressed. As such, political policies that decrease the salience of this wicked problem and increase the

quality of healthcare that people receive, while bearing in mind the complicated nature of the problem, must be enacted. The Community Choice Act answers this call.

Recommendation

My recommendation is that the Community Choice Act should be enacted on a national level. The Community Choice Act would help improve the personal autonomy of those who are disabled and elderly by providing them with an option to receive care that can be personalized to meet their genuine needs or legitimate wants within their own community. While this may seem like a minor issue to some, the ability to choose where you wake up, if you are removed from your family or not, and who helps you dress in the morning are all choices that those who are not currently experiencing dependency take for granted. Without the CCA, many disabled and elderly people in the United States of America do not have the ability to make these choices about their own daily lives and are at risk of receiving care with paternalistic tendencies. Moreover, those who are dependent also experience stigma. By reducing the amount that those with dependency are removed from society, and instead fostering their integration within communities, the stigma against states of dependency that is experienced by many disabled and elderly people will lessen. Furthermore, the CCA does not come at a large financial burden and could even be significantly cheaper than paying for care at a care institution. Streamlining the various different state versions of the CCA under one plan would also increase public knowledge about the CCA and the efficiency of the program. Lastly, the CCA receives overwhelming public support from the American public who recognize the importance of providing respectful and personalized care to those who experience dependency.

Conclusion

My hope in writing this thesis is to evaluate and challenge how society perceives and reacts to disability. Regardless of whether or not the origin of disability is biological or social, it is irrefutable that our society, policies, and even our philosophical ideas and theories are composed in such a manner which normalizes and assumes certain physical characteristics, and otherizes biological features that do not fit within this norm. The questions then become: how do we challenge this norm? And how can we better respond to physical and mental differences in people that society currently classifies as disabling? It is my belief that Eva Kittay's theories on disability answer both of these questions. If society develops a better understanding of the inevitable dependency that all humans experience, the necessity and dynamics of proper care in response to dependency, and the joy and quality of life that can be felt by those who experience dependency, dependency and disability will start to become normalized and the identity of 'disabled' will become less salient. This is not to say that I think that disability should be ignored, on the contrary, I believe that disability should be addressed on an individual, societal, and political level insomuch that the current negative aspects of disability and dependency are decreased.

To achieve this aim and provide the care that dependency requires, certain political policies are necessary. As argued by Kittay, care does not occur within a vacuum and thus society must craft policies that make equitable care relationships possible. I believe that enacting a national Paid Family Leave program and the Community Choice Act would help support and validate dependency relationships and improve the lives of those who experience dependency. Without the implementation of such policies that are informed by the theories developed by Kittay, we cannot hope to live in a world where the philosophical ideas we formulate on

disability have a felt impact on those who experience dependency. Similar to care, both philosophy and political policy do not live in a vacuum. Each must acknowledge the other if philosophical ideas are to be implemented and thoughtful and informed political policy enacted.

Similarly, successful political policy cannot be enacted without considering certain political realities, such as those addressed in the political theory on wicked problems and the issue-attention cycle. To leave these realities untouched would be to introduce policy into the world without giving proper thought to the dynamics present within the environment that is being affected. Such considerations become progressively more pertinent as our social world becomes increasingly individualistic, our political world more removed, and our economic resources strained as we try to address the problems within our society. While the current political climate may not appear to lend itself to the implementation of the aforementioned policies, Covid-19 has taught the world the value of care. A pandemic which has separated families from each other's care, requires highly personalized care, and has put thousands into a state of dependency, has also highlighted the presence of dependency in our lives and the need for the implementation of philosophical ideas on care ethics and dependency. Dependency and disability are not limited to those who 'look' disabled. Instead, dependency has an omnipresent impact on society, creating a world where humanity exists in an interconnected network of dependency relations. Thus, despite the political and economic realities the world may be facing, the need for philosophically inspired political policies addressing disability and dependency is omnipresent and cannot be left unaddressed.

Works Cited

- Burwell, Sylvia Mathews. "Community First Choice: Final Report to Congress." Community First Choice (CFC) 1915 (k). Medicaid, December 2015.
<https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/community-first-choice-cfc-1915-k/index.html>.
- "Community Choice Act National Kickoff Draws Thousands ." ADAPT. ADAWatch, March 24, 2009. <https://adapt.org/wp-content/uploads/2009/10/Incitement-2009-Volume-22-no.8.pdf>.
- Connecticut Paid Family & Medical Leave. CTPFMLA, 2020.
https://ctpaidleave.org/s/?language=en_US.
- CT Campaign for Paid Family Leave. CWEALF. Accessed January 6, 2021.
<https://paidfamilyleavect.org/>.
- Diament, Michelle. "Poll Shows Public Support For Community Living." Disability Scoop, May 24, 2010. <http://www.disabilityscoop.com/2010/04/28/poll-community-living-act/7854/>.
- Disabled World. "Health Care Reform, The Community Choice Act, and People with Disabilities." Disabled World, June 29, 2010. <http://www.disabled-world.com/disability/awareness/community-choice-act-disability.php>.
- Downs, Anthony. "Up and Down with Ecology-the Issue-Attention Cycle." *Public Interest* 28 (1972): 38–50.
- Eiken, Steve. "Community Choice: New Jersey's Nursing Home Transition Program." ASPE. US Department of Health and Human Services , February 21, 2017. <https://aspe.hhs.gov/basic-report/community-choice-new-jerseys-nursing-home-transition-program>.
- "Family and Medical Leave Act." U.S. Department of Labor Seal, 2020.
<http://www.dol.gov/agencies/whd/fmla>.
- Gibson, Piper. "Our State's Future Depends on Paid Leave." CT Campaign for Paid Family Leave, September 23, 2019. <https://paidfamilyleavect.org/2018/05/21/cts-future-depends-on-paid-leave/>.
- Granato, Madeline. "Twenty-Six Years after FMLA, Paid Leave Is Coming to CT." The CT Mirror, August 5, 2019. <https://ctmirror.org/category/ct-viewpoints/twenty-six-years-after-fmla-paid-leave-is-coming-to-connecticut/>.
- Hackett, Elizabeth, Sally Anne Haslanger, and Martha C Nussbaum. "Human Capabilities, Female Human Beings." Essay. In *Theorizing Feminisms: a Reader*, 124–39. New York, NY : Oxford Univ. Press, 2006.

- Hayes, Tara O'Neill, and Margaret Barnhorst. "How Children Benefit from Paid Family Leave Policies." American Action Forum, June 9, 2020.
<https://www.americanactionforum.org/research/how-children-benefit-from-paid-family-leave-policies/>.
- Horowitz, Juliana Menasce, Kim Parker, Nikki Graf, and Gretchen Livingston. "Americans Widely Support Paid Family and Medical Leave." Pew Research Center's Social & Demographic Trends Project. Pew Research Center, July 31, 2020.
<https://www.pewresearch.org/social-trends/2017/03/23/americans-widely-support-paid-family-and-medical-leave-but-differ-over-specific-policies/>.
- "Hundreds of Advocates Pack the House for CCA!" Community Choice Act Action Hub. National Council on Independent Living, January 16, 2008.
<https://web.archive.org/web/20090702131444/http://www.ncil.org/news/CCAActionHub.html>.
- Kittay, Eva Feder. "Centering Justice on Dependency and Recovering Freedom." *Hypatia* 30, no. 1 (2015): 285–91. <https://doi.org/10.1111/hypa.12131>.
- Kittay, Eva Feder. *Learning from My Daughter: the Value and Care of Disabled Minds*. New York, NY, NY: Oxford University Press, 2019.
- Kittay, Eva Feder. *Love's Labor: Essays on Women, Equality and Dependency*. New York, NY: Routledge, 1999.
- Kittay, Eva Feder. "Taking Dependency Seriously: The Family Medical Leave Act." *Hypatia* 10, no. 1 (1995): 8-29.
- Kittay, Eva Feder. "The Ethics of Care, Dependence, and Disability." *Ratio Juris* 24, no. 1 (2011): 49–58. <https://doi.org/10.1111/j.1467-9337.2010.00473.x>.
- Kittay, Eva Feder. "The Personal Is Philosophical Is Political: A Philosopher And Mother Of A Cognitively Disabled Person Sends Notes From The Battlefield." *Metaphilosophy* 40, no. 3-4 (2009): 606–27. <https://doi.org/10.1111/j.1467-9973.2009.01600.x>.
- Kittay, Eva Feder., Yayo Okano, Kazue Muta, and Eva F Kittay. "From the Ethics of Care to Global Justice." Essay. In *Justice Rooted in an Ethics of Care: Reconceiving Equality*, 113–20. Tokyo, 2011.
- LaFleur, Jennifer. "Nursing Homes Get Old for Many With Disabilities." ProPublica, June 21, 2009. <http://www.propublica.org/article/nursing-homes-get-old-for-many-with-disabilities-621>.
- Nussbaum, M. C. (2006). *Frontiers of Justice: Disability, Nationality, Species Membership (The Tanner lectures on human values)*. Cambridge, Massachusetts: Harvard University Press.

“Olmstead: Community Integration for Everyone .” ADA. Accessed January 11, 2021.
http://www.ada.gov/olmstead/olmstead_about.htm.

Rittel, Horst W J, and Melvin M Webber. “Dilemmas in a General Theory of Planning.” *Policy Sciences* 4 (1973): 155–69.

Saner, Emine. “‘There Is a Fear That This Will Eradicate Dwarfism’: the Controversy over a New Growth Drug.” *The Guardian*. Guardian News and Media, September 28, 2020.
<https://www.theguardian.com/science/2020/sep/28/there-is-a-fear-that-this-will-eradicate-dwarfism-the-controversy-over-a-new-growth-drug>.

Stone, Deborah A. *Policy Paradox: the Art of Political Decision Making*. New York City, NY: W.W. Norton & Co., 2012.

Uhde, Zuzana. “On Sources of Structural Injustice: A Feminist Reading of the Theory of Iris M. Young.” *Human Affairs* 20, no. 2 (2010). <https://doi.org/10.2478/v10023-010-0016-x>.

Wasserman, D., Asch, A., Blustein, J., & Putnam, D. (2016, May 23). Disability: Definitions, Models, Experience. Retrieved November 13, 2020, from
<https://plato.stanford.edu/entries/disability/>

Young, Iris Marion, and Danielle S. Allen. *Justice and the Politics of Difference*. Princeton, New Jersey: Princeton University Press, 2011.