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Broadening the Boundaries of Agency: Cognitive Disability, Agency, and Autonomy

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Broadening the Boundaries of Agency: Cognitive Disability, Agency, and Autonomy

by

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Abstract

The aim of this thesis is to create a broader framework for agency that is inclusive of persons with cognitive disabilities. The first chapter establishes that persons with cognitive disabilities have historically been excluded from making decisions, and their autonomy was neglected and disrespected. Rather than being integrated into society and assisted with making decisions, persons with cognitive disabilities either had their decisions made for them or were manipulated into situations that they may not have chosen. “Agency” and “autonomy” were narrowly understood as correlating with individuals exercising their intellectual decision-making capacities rather than with joint projects that people can partake in together. The social structure that can restrict or enable one’s agency was ignored. Since agency was “individualized” and since persons with cognitive disabilities are often located in environments where they are helped by caregivers and trustees who assist them in making decisions, it is not surprising that cognitively disabled persons were historically marginalized from liberties that were associated with decision-making.

In an effort to broaden agency and autonomy to include cognitively disabled persons, the second chapter explores literature that incorporated the social environment into our understanding of agency. Two models or schemas that feature in the literature on cognitive disability and agency are paternalistic models and extended mind models. Both models have their flaws. Paternalistic models overemphasize how persons without cognitive disabilities restrict the decision making powers of persons with cognitive disabilities. Extended mind models have philosophical issues related to their ontological claims. There is also the associated moral worry that if extended mind theory is true and we understand trustees as extensions of the

disabled individual, then there is a risk of negating the humanity of the trustee or the cognitively disabled person. Extended mind models risk treating caregivers, proxy decision-makers, and trustees as objects because they reduce them to the functional parts that are used by the person needing help. Rather than acknowledging the caregiver as a person with a will, biases, beliefs, well-being and intentions, extended mind theories threaten to leave central parts of the caregiver's humanity unacknowledged. A better theory of agency incorporates both the caregiver and the disabled individual into the schema with the important features of their humanity acknowledged.

The third and fourth chapters attempt to ameliorate the problems that are highlighted in the second chapter by presenting and defending a framework that interprets care relationships, and the help that one receives when acting inside them, as a type of shared agency. I call this framework "helped agency" (HA). The HA framework ameliorates the issue associated with the paternalistic model, because it expands the decision making powers of persons with cognitive disabilities to include situations where persons with these disabilities can be helped by trustees to make self-governing decisions. It also avoids worries associated with understanding care relationship within an extend mind theory because the HA theory integrates helpers as central figures of the decision-making process. This theory includes both the cognitively disabled person and the caregiver, since both characters play integral parts in decisions and actions. Thus, it is a better framework for understanding the agency and autonomy of cognitively disabled persons, and it respects the dignity of the helper and disabled individual better than other theories presented in the literature.

The conceptual framework of HA can also expand to encompass when the non-disabled are helped. We are all equal because we all require assistance from time to time. We all face

situations where we need another's assistance to accomplish difficult tasks. When we are young, we all require the helping care that is described by HA. As we age, we may require more assistance from others when we begin to feel the corporeal effects of old age. Furthermore, with current advances in medical sciences that can extend our lives with treatments and not entirely cure us, the population of physically and cognitively disabled persons grows and changes. To embrace HA in the situations where we need help from others and provide assistance when needed is to embrace at least one aspect of how we are agents and how we are autonomous. By acting with HA as a practical guide, one can respect the dignity and autonomy of persons who may struggle to make decisions alone, and respect the dignity of those who provide care. To acknowledge HA is to appreciate another way of being human that has been previously underappreciated: being helped to accomplish tasks and helping others to accomplish their goals. HA broadens the boundaries of agency and autonomy to encompass persons with cognitive disabilities so that policies can be formed to empower them to carry out plans of action consistent with their interests and values. With HA as an operating assumption about how persons with cognitive disabilities make decisions, policies and practices can be created so that persons with cognitive disabilities can be appropriately acknowledged and morally responded to as autonomous agents. In sum, persons with cognitive disabilities have dignity to be respected, and it is through HA that we begin to understand how we can respect it.

To those who have provided me care and assistance.

&

To my friend Kennedy,
who has dedicated her life's work to caring for and helping others.

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Introduction

Philosophical ideas about agency and autonomy are too narrow and need to be broadened to encompass cognitive disability. This is one of the central claims that I present and defend in this thesis. I do so with the intention of carrying on a tradition of inclusiveness that can be observed in disability studies literature and disability rights activism. Historically, the concept of disability has been closely tied to exclusion. In the article “Disability: Definitions, Models, Experience” David Wasserman, Adrienne Asch, Jeffrey Blustein and Daniel Putnam assert that the word “disability” has often been used synonymously for “inability” or to impose limitations on rights and powers (Wasserman, Asch, Blustein, & Putnam, 2011). Following Wasserman and colleagues’ description, from the very beginning, it would appear that the classification of disability was used to exclude or control particular kinds of people. More specifically, the classification of disability was used to exclude certain people from the work force. During the disability rights movement in the late 1900’s a group of activists sought to shift the thinking of disability by presenting a different model to reflect their active concern to include disabled people in public life. While the medical model understood disability as primarily a physical or mental impairment, the social model sought to include persons with disabilities by construing disability as a relation between individuals and exclusionary social environments (Finkelstein, 2001). The social model provided the political impetus for disabled people and their allies to actively seek and demand changes in social environments to make them more accessible and inclusive for persons with atypical modes of performance. This social model attempted to broaden our understanding of disability to allow persons with disabilities to participate in society.

Since the rise of the disability rights movement, social models have come under intense scrutiny for excluding both the body and impairment within the conceptual framework of

disability. Mike Oliver, a major proponent of social models of disability, argues that illness, impairment, and their emotional sequelae belong to the personal and private domain (Oliver, 1996). Oliver further argues that impairments are poor foci for political organization and dwelling on impairment takes attention away from social factors that causally construct disability (Oliver, 1996). Vic Finkelstein, another proponent of social models, echoes his concern and assumes that introspective dwelling on personal experiences of impairment, or encountering barriers and bringing them into the public eye, diverts disabled people's energies away from changing society (Finkelstein, 1996). Against Finkelstein and Oliver, feminists argue that inclusion of "impairment experiences" in disability theory and bioethics is useful on political grounds, because disablilism cannot be challenged without acknowledging the experience of living with impairment. Along these lines, the feminist philosopher Susan Wendell argues that "much of the experience of disability and illness goes underground, because there is no socially acceptable way of expressing it and having the physical and psychological experience acknowledged. Yet acknowledgement of this experience is exactly what is required for creating accessibility in the public world. The more a society regards disability as a private matter, and people with disabilities as belonging in the private sphere, the more disability it creates by failing to make the public sphere accessible to a wide range of people." (Wendell, 1996, p. 40) So, feminists critique the social model because it tended to marginalize and neglect the contribution impairment and the body makes to understanding disability. Disability feminists broadened the scope of what was counted as important to understand disability by including impairment and bodily experiences of persons with disabilities into the conceptual framework (Morris, 1992, 1993, 1996; Scully, 2008, 2009). They also broadened the public understanding of what sort of discourses were allowed to be heard or discussed to garner political support for persons with disability.

Cognitive disability has also been relegated to the margins of intellectual exploration within disability studies. Why? The medical sociologist Carol Thomas plausibly says, “Disability studies has concentrated, in a now contested fashion, on the disablist social barriers that *physically* impaired people confront. The growth and interest in ‘difference’ and ‘the impaired body’ has only just begun to turn disability studies writers’ attention to the workings of ‘the mind’.” (Thomas, 2007, p. 131) My thesis confronts this bias directly and acknowledges the experience of cognitive disability and intellectual impairment. It explores cognitive disability along with its many philosophical implications. More specifically, I argue that there is a large precedence in philosophy to marginalize the agency of cognitively disabled persons, so that it is unacknowledged or disrespected. Therefore, I expand the conceptual framework of agency to include cognitively disabled persons and spell out how they too can be counted as fully autonomous agents.

Part of my thesis draws on contested intuitions about the dignity and respect granted persons with cognitive disability. It will be useful to provide a short interlude on dignity with respect to the agency and autonomy of individuals. Dignity is a problematic notion within bioethics, but even its most vehement critics recognize the importance of respect for autonomy within medical ethics. Ruth Macklin argues that dignity is a useless concept and can be eliminated without losing anything important to the practice of medical ethics. Instead, she argues that dignity refers to the idea that “one is a person whose actions, thoughts and concerns are worthy of intrinsic respect because they have been chosen, organized and guided in a way that makes sense from a distinctly individual point of view.” (Macklin, 2003) The concept of dignity, according to Macklin, is a hopelessly vague substitute for the principle of respect for persons or respect for autonomy (Macklin, 2003). In “Human Dignity and Respect for Persons: A Historical Perspective on Public Bioethics” Daniel Davis plausibly argues that Macklin’s critique of human

dignity is open to question. He asks, “In what sense is respect for persons the principle of medical ethics? Does respect for persons mean the same as respect for autonomy? Does either principle fully exhaust the meaning of human dignity? Is dignity really reducible to autonomy?” (Davis, 2008, p. 20) Davis goes on to suggest that the principle of respect for persons “embraces two ‘ethical convictions’...One of the two convictions is that individuals should be treated as autonomous agents,’ and its corresponding requirement is to ‘acknowledge autonomy.’ The other conviction is that ‘persons with diminished autonomy are entitled to protection,’ and its correlative requirement is to ‘protect those with diminished autonomy.’” (Davis, 2008, p. 24)

Davis rightly understands autonomy as a concept that is important to human dignity. However, one may ask Davis: what does it mean to exercise one’s autonomy? Is autonomy tied to the capacity to deliberate about one’s personal goals and act in accordance with this deliberation? Davis asserts that it is, and respect for this process is given by refraining from obstructing one’s actions, unless they are clearly detrimental to others. But uniting respect for autonomy with the capacity to deliberate has direct implications for persons with cognitive disabilities. Are persons with cognitive disabilities really incapable of autonomous agency? Does this idea not exclude persons with cognitive disability from meaningfully contributing to decisions about their own well being? I suggest that these persons are capable of being autonomous agents, and further reflection on respect for autonomy requires more philosophical development with special attention paid to cognitive disability. In this thesis, I broaden the scope of agency and autonomy to include persons with cognitive disabilities. In this way, I contribute to the philosophical development of dignity and carry on the tradition in disability studies that seeks to include persons with various impairments in social participation.

In the first chapter, I provide a brief history of cognitive disability with special attention paid to the thoughts and opinions of philosophers and the implications that their ideas have for

persons with cognitive disabilities. Through examining the history of the beliefs, attitudes and practices in response to cognitive disability, there appears to be a tendency to disrespect the agency and autonomy of persons with cognitive disabilities. Part of this disrespect is based on the assumption that persons with cognitive disabilities have no agency to be respected, because of their cognitive limitations. With these assumptions in place, the social environment is often ignored when the agency and autonomy of persons with cognitive disabilities is considered, much to the detriment of properly understanding the agency of cognitively disabled persons.

Specifically, persons with disabilities are in social environments that include trustees and caregivers who can assist them. These helpers take over for whatever rational deficits are lost, and this fact was generally ignored in past explorations of agency and autonomy. I conclude the chapter with some reflection on possible directions for future enquiry, and recommendations for how to respect the autonomy of persons with cognitive disabilities.

The second chapter explores the idea that cognitively disabled persons can be assisted by other individuals, and the social environment of cognitively disabled persons needs to be acknowledged. Rather than ignore the social environment of cognitively disabled individuals, I affirm it and attempt to fit it into a broader schema for understanding agency and autonomy. Two topics that are explored in this chapter are paternalism and extended agency. Paternalism is when another agent wholly takes over decision-making tasks of a cognitively disabled person, specifically when a cognitively disabled person severely lacks any capacity to make decisions. Paternalism suggests that one's social environment can restrict certain decision-making powers. On the other hand, a social environment can also consist of persons who are willing and able to enable a cognitively disabled person make decisions. One potential way of elucidating this phenomenon is by borrowing from the extended mind theory. Extended mind theorists argue that external elements in the environment can constitute part of a person's cognitive system.

Therefore, trustees or caregivers may function as part of the cognitively disabled person's agency. This theory implies that the trustee who aids the cognitively disabled person is an extension of them, and may function like a cognitive prosthesis. I present extended mind theory and explain how the theory might be utilized to provide a conceptual framework for the agency of cognitively disabled persons. Next, I present a number of objections and concerns for extended mind theory along with a moral worry that if trustees are an extension of the cognitively disabled person, then this threatens to undermine the agency and humanity of both the trustee and the cognitively disabled person. I conclude the chapter by recommending a different theory that fully incorporates both agents into the conceptual framework of care relationships.

In the third chapter, I present the recommended conceptual framework for understanding care relationships. This conceptual framework incorporates all agents into the framework, and understands all parties involved as worthy of respect. I argue that rather than understanding the caregivers as an extension of the cognitively disabled person, helped actions should be understood as a shared cooperative activity. One philosopher who has developed an intricate account of shared agency is Michael Bratman, whose ideas I liberally incorporate into my own account. I briefly spell out some conditions for shared agency, and philosophically explore how these conditions may be relevant to analyze the autonomous agency of persons with cognitive disabilities. However, I make some relevant distinctions that may separate helped actions from shared actions. Therefore, the theory I recommend is similar to shared agency, but contains crucial differences. To account for these differences, I call this theory "helped agency" or "helping agency" (HA). However, it is entirely possible that HA is within the same family as shared agency. This makes it linguistically complicated to classify, because a helped action may still be a shared action, similar to a shared action, or different from a shared action; all of these descriptions may pragmatically fit with HA. Regardless, HA seems to be the best theory for

understanding care relationships that include trustees, caregivers and cognitively disabled persons.

In the final chapter I entertain three possible objections to understanding care relationships as HA. The first objection argues that HA is not the best conceptual framework for understanding care relationships. I argue that this objection fails. The second objection raises troubling concerns regarding cases when relevant cognitive impairments, like those present in autism, imply that individuals may have difficulty cooperating in joint actions. In reply to this objection, I acknowledge the challenges that certain forms of autism present for participating in a joint action. But rather than accepting that the existence of these autistic individuals implies that HA is false, I argue that understanding a care relationship within the framework of HA actually helps us to understand the unique care challenges that are encountered when providing care for autistic individuals. Autism presents a complication to HA, not a sound objection.

Finally, the third objection relies on the idea that trustees are fallible when ascribing agency and capacities to the people they are supposed to be helping, and this fact causes a problem for the theorist who embraces HA. To make this objection more salient, I present the details of cases involving facilitated communication, where facilitators inaccurately project communication capacities onto cognitively disabled persons. In these cases, facilitators believe they are helping the disabled person communicate with others. But it is facilitator who communicates and not the impaired individual. In reply to this objection, I argue that trustees may be fallible with respect to ascribing agency to others, but they are not systematically wrong. It is not clear that they are wrong all or most of the time. In fact, it seems plausible that they can still accurately ascribe agency some of the time. Thus, the objection based on fallibility misappropriates how fallible trustees are with respect to how many times one accurately ascribes agency and capacities to another. While some of the objections presented in the fourth chapter

offer interesting complications to HA that need to be acknowledged, they do not constitute a valid and sound objection to my overall thesis. HA still stands as the best conceptual framework for understanding care relationships and the autonomy of most persons with cognitive disabilities.

Chapter 1: Bioethical Lessons in Agency from the History of Cognitive Disability

It has historically been assumed that rationality is an indication of humanity and agency. Immanuel Kant, for example, argues that human dignity is grounded in our rational nature. The assumption was that there is something special about human beings, a status giving them an advantage over other creatures in the natural world due to their distinct ability to deliberate, form intentions, and make decisions. The problem with intertwining humanity with rationality is it has profound consequences for persons who have a diminished capacity for rational deliberation. Given that there has been a general assumption regarding the role of rationality in agency and an individual's proficiency in exercising certain cognitive capacities, there has been differential treatment of persons who struggle to function in a society that requires proficiency in exercising some cognitive abilities. These include persons with autism, Alzheimer's disease, and intellectual and developmental disabilities (IDD). For the purposes of this discussion, it is important to distinguish neurodevelopmental disabilities and neurodegenerative disabilities. The former begin at birth and include autism and cerebral palsy and the latter occur later in life and include Alzheimer's and other dementias.

The task of this chapter is to briefly examine past treatment and beliefs regarding cognitive disability, agency, and autonomy. "Agency" refers to the ability to make decisions and translate them into actions, and "autonomy" is the ability to direct one's self or self-governance. I argue that there is historical evidence that the agency and autonomy of persons with cognitive disabilities has traditionally been disregarded or disrespected. In this section, I present historical examples regarding the attitudes and treatment of persons with cognitive disabilities, and I pay particular attention to the philosophical notions of agency and autonomy. I will conclude with

some recommended areas for further bioethical consideration on how to regard and respect the agency and autonomy of persons with cognitive disabilities.

Traditionally, cognitive disability has not been a topic of concern within philosophy, despite the emphasis that has been placed on rationality and the value that has been placed on the intellect.¹ Noting this troubling philosophical trope, Eva Kittay and Lucia Carlson write, “the subject of cognitive disability remains somewhat marginal in philosophical discourse...people with cognitive disabilities rarely appear in historical philosophical texts, when they are mentioned they are referenced only to be discounted as irrelevant or as exceptions that prove the rule.” (Carlson & Kittay, 2010, p. 3) Following Carlson and Kittay’s lead, one can note a few unreflective and unjustified remarks from philosophical literature which provide some indication about how philosophers from the past have thought about persons with cognitive impairments.

A preliminary remark should be made before presenting and critically examining the history of attitudes and treatment of persons with cognitive disabilities. Persons with cognitive disabilities and those who count as unskilled in exercising intellectual talents are not a single, homogeneous group that we can examine throughout the ages. Each point in history has different definitions and assumptions attached to *who* counts as cognitively disabled, and intellectually deficient. Furthermore, each disability or impairment comes in varying degrees, and different theories and explanations are offered for why persons with intellectual disabilities are the way they are, and how they ought to be treated. For example, before Alois Alzheimer’s observation of patient Auguste Deter’s symptoms in the first years of the twentieth century, there was no official

¹ Both rationality and intellect are two different concepts. Rationality denotes one’s ability to achieve one’s goals, or the capacity to acquire justified beliefs. Intelligence denotes a computational power to solve a problem, or one’s IQ.

diagnosis of what is now known as Alzheimer's disease. Additionally, with scientific advances in neurobiology, there arose different ways of diagnosing, understanding and treating those with cognitive disabilities and behavioral abnormalities that were not available in the past. With this preliminary remark in mind, one should not abandon examining the past treatment and attitudes of persons with cognitive disabilities, because disturbing trends about how one classified and morally treated those with intellectual disabilities can and should be identified. This moral treatment includes attitudes and actions about how "normal" agents ought to act towards cognitively "abnormal" persons and includes both medical treatment and treatment of persons with respect. The disturbing trends, I believe, provide powerful lessons for continual medical and/or moral treatment of persons with cognitive disabilities and neurological disorders. We have much to learn from them.²

1.1. Ancient and Medieval Philosophy

Ancient philosophers assumed that there was no genuine distinction between people with learning disabilities and those with other forms of disabilities. Equally malicious treatment was recommended both for persons with cognitive disabilities and for persons with physical disabilities. In the ideal state of Plato's *Republic* persons with disabilities are required to be exposed to the elements. Plato regards the lives of persons with disabilities as so problematic that they should be eliminated from existence (Plato, 460 c). In the *Politics*, Aristotle similarly recommends that there should be a law "that no deformed child shall be reared." (Aristotle, 1335

² I make no non-overlapping distinction between moral and medical treatment. In the present work, moral treatment is a broader category and can include actions that are not necessarily medical. Medical treatment, on the other hand, is normally accompanied by moral decisions made towards a patient. In other words, medical treatment involves an informed judgment about the best course of action.

b) According to Aristotle, persons with visible deformities or odd behaviors would be better off not existing for the sake of the greater social good. This reflects the value that Plato and Aristotle –and indeed many other philosophers- place on rationality.

Both Aristotle and Plato were most likely informed by larger social attitudes about disability that were exclusionary towards persons with disabilities. One example of exclusion of these persons can be found in the ancient standards of priesthood, where absence of physical disability or deformity was a qualification for this profession. Robert Garland argues that Plato agreed with this practice and writes: "Plato in the Laws laid it down that a priest should be sound in body, and there is plentiful evidence to indicate that good looks were not only a strong recommendation for any candidate to a priesthood, but even an essential condition." (Garland, 1992, p. 39) In times of crisis, ancient Greeks additionally used physically disabled persons as scapegoats wherein all of the troubles that beset the community were thought to be the responsibility of the ugly or disfigured (Garland, 1992, p. 41). Finally, there is some evidence that in ancient Greece those with cognitive impairments could easily be manipulated, and such manipulations were morally permissible. Garland states, "their low IQ made cretins ideal accomplices to illicit love affairs...In another epigram a guest observes how an adulterous pair make use of such a person to pass lascivious kisses slyly back and forth by proxy under the eyes of the woman's unsuspecting husband." (Garland, 1992, p. 43) The general attitude in Greek antiquity towards persons with impairments reflected a social trend about those labeled as imperfect: one of marginalization, ridicule, social disdain, exclusion, manipulation and isolation.

Although it may be tempting for us to separate ourselves from the morally abhorrent beliefs of Greek antiquity, we should be reminded that we too live in a society that sometimes regards persons with disabilities as objects of derision or amusement. Furthermore, we continue to perceive persons with physical disabilities, diseases and cognitive impairments as a problem to

be eliminated through preventative or curative measures. I *tentatively* suggest that persons with these conditions are perceived as problematic, because while one philosophical view argues for an identity relation between these conditions and the persons who have them, another view argues for a non-identity relation. According to the non-identity theory there is a distinction between the person with the impairment and the impairment itself. It is this, rather than the person, that is perceived as problematic. It is therefore the impairment that is to be eliminated, not the person. There could be some bioethical debate about whether there is an identity relation between the person and impairment, but the social *perception* of impairment and disability is not so easily distinguished from the person. Indeed, the social reaction to persons with cognitive disabilities -resulting in social disdain, isolation, marginalization, erroneous assumptions and exclusion- suggests that we do not readily separate impairment and disability in our day-to-day lives.³ We often still react to the person with the impairment as a problem to be fixed or cured. In this respect, Western attitudes towards persons with disabilities are descended from our classical past.

During the middle ages, a distinction was made between learning disabilities and other forms of disability (Atherton, 2007). I suspect that such a distinction was made, in part, because of the religiously inspired separation of the soul and the body. In *Summa Theologica*, Thomas Aquinas writes of a person blind in mental or intellectual sight – presumably he means someone with a diminished intellectual capacity. The central idea for Aquinas is that one's rationality is united with the eternal soul, and an intellectual disability is a prevention of the soul to exercise its

³ Persons with disabilities, on the other hand, are mixed in how they conceive and perceive disability. Some prefer to refer to themselves as “persons with a disability”, which indicates a separation of disability and personhood, with an emphasis on the “person”. Others prefer “disabled person”, because they strongly identify with their disability and impairment.

proper function. The prevention occurs at a lower level wherein the human intellect is kept from what it needs to properly understand, think, or rationalize. Aquinas writes:

Just as bodily blindness is the privation of the principle of bodily sight, so blindness of mind is the privation of the principle of mental or intellectual sight. Now this has a threefold principle. One is the light of natural reason, which light, since it pertains to the species of the rational soul, is never forfeit from the soul, and yet, at times, it is prevented from exercising its proper act, through being hindered by the lower powers which the human intellect needs in order to understand, for instance in the case of imbeciles and madmen, as stated in I, 84, 7,8.

It is difficult to see what Aquinas might mean by the above cryptic passage. But one can plausibly assume that the "lower power", which Aquinas describes as hindering the rational soul, is a hindrance of a particular corporeal nature, and an intellectual impairment arises out of a lack when using one's eternal reason. Aquinas' explanation of cognitive disability was imbued with theological ideology, and the so-called "lack" that occurs in cognitive disability was understood as a result of original sin, whereby a schism occurred, which caused a disconnection between God and mankind. After original sin, lower powers of the body were put in a state of disorder in relation to the higher powers of the rational soul (Romero, 2012, p. 112). According to Aquinas, one lacks the ability to self-govern or be an agent, if one is afflicted with a lack that causes mindlessness or hinders one's use of reason.

A significant trend during the medieval period was to ascribe supernatural forces to cognitive disabilities, and this led to a fear or worship of persons with cognitive disability. In a literary analysis, Carl Haffter draws a correlation between physical appearances and behavior of some persons with cognitive disabilities and the descriptions of changelings found in European folklore (Haffter, 1968). A changeling was an infant that resembles the description of persons

with a disability, who was deviously left behind as a replacement by fairies after the true, good, infant was stolen from parents. Subsequently, a frequent tactic in these stories was to outwit a changeling, which suggests a disdainful literary attitude about persons with cognitive disabilities. In essence, they could be manipulated, and such manipulations were generally allowed and encouraged by society (Atherton, 2007).

One can compare the fictitious treatment of changelings with current social trends to morally allow for psychological manipulation and control or limit the autonomy of cognitively disabled individuals. In other words, the response to persons with cognitive disabilities was to change the perception or behavior of others through underhanded or deceptive tactics by advancing the interests of the manipulator, usually at some expense to the person being manipulated. More specifically, as we will see later, the tactic of manipulating persons with certain psychological vulnerabilities was a disturbing element in the forced sterilization movement. To add an additional personal account, when attending high school I witnessed a group of young boys who convinced a younger student with down's syndrome, whom I will call "Nathan", that it would be fun and harmless to show the middle finger to his teachers. As the boys watched in amusement, Nathan did as the boys convinced him, and he got into trouble. The boys believed that there was nothing objectionable about manipulating Nathan for their amusement and certainly did not respect or recognize the autonomy or agency of Nathan. Instead, they used him instrumentally for their own selfish amusement and thus violated the second formulation of Kant's categorical imperative to never use others merely as means, but also as ends in themselves. Furthermore, while Nathan had some capacities required for making decisions and self-governance, this capacity was manipulated and/or ignored. It is precisely this manipulation and lack of recognition of the capacities of persons with cognitive disabilities that was so morally wrong in the past, and continues to be today.

If we take Aquinas' view of cognitive disability seriously, we can recognize the implication that persons with cognitive disabilities lack certain capacities to self-govern due to their own corporeal reality. According to the views discussed thus far, agency was posited as a matter of an individual person exercising one's cognitive capacities, and little attention was paid to the social context of individuals with cognitive disabilities. Against this assumption about agency, persons with cognitive disabilities exist within social contexts that can restrict or promote the exercise of a person's decision-making capacities. The restriction or exercise of the decision-making capacities of persons with cognitive disabilities, in many cases, crucially relies on the social contexts in which they live. If agency is understood strictly in terms of individuals exercising their cognitive capacities, with no attention being paid to the possibility of being helped -or hindered- to make decisions by others, then this has implications for whether a person with a cognitive disability is treated as an autonomous agent. Context and a person's social environment should be taken into account when considering the agency of persons with cognitive disabilities and whether their actions are their own.

In sum, during antiquity and the Middle Ages there were a number of common threads running through the perception and treatment of persons with cognitive disabilities. Persons with disabilities were treated with disdain, marginalized, excluded and manipulated, and the recommendation of some philosophers was to leave deformed children to the elements. The medieval tradition brought religious ideologies attached to cognitive disabilities, along with a continued assumption that persons with disabilities were of lesser value because of their disability. This made it permissible for them to be psychologically manipulated. One prominent line of thought and treatment throughout the ancient and medieval periods was an implicit disregard for the autonomy and agency of persons with cognitive disabilities. Furthermore, certain philosophical theories failed to take account of the social environments in which persons

with cognitive disabilities existed and failed to acknowledge that the perception and response to these disabilities was shaped by these environments.

1.2. Modern Philosophy

In the modern era of philosophy, with its exploration of enlightenment and freedom, one would expect to find an ethos of civility regarding the attitudes towards and the treatment of persons with cognitive disabilities. A closer look reveals that this is not the case. From the philosopher John Locke, we find the assumption that persons with cognitive disabilities cannot be free because of their natural impairments. In the *Two Treatises on Government* he writes, “through defects that may happen out of the ordinary course of Nature, any one comes not to such a degree of Reason, wherein he might be supposed incapable to know the law... he is never capable of being a Free Man, he is never let loose to the disposal of his own Will... And so Lunatics and Ideots are never set free from the Government of their Parents.” (Locke, 1824) According to Locke’s understanding of cognitive disability, those with sufficient cognitive impairments can never be capable of being free, autonomous citizens capable of self-governance.⁴

A similar view about agency and autonomy can be attributed to Immanuel Kant. Kant regards autonomy as “the basis of the dignity of human and of every rational nature.” (Kant,

⁴ I assume Locke argues that impairments come in degrees, and that freedom depends on the degree of the impairment. One might argue that Locke means that anyone with any cognitive impairment could not be free, but this alternative is clearly vulnerable to counter examples. So, for the sake of charity, I wish to entertain the strongest position available: that impairment comes in degrees, and freedom depends on the degree of the impairment. Furthermore, in the passage quoted, Locke mentions “a degree of Reason”, which could imply he held a threshold view.

1959, p. 59) According to Eva Kittay's analysis of Kant, only persons can make autonomous decisions, and personhood is conceptually united with rationality. Therefore, it can be inferred that those with cognitive disabilities are rationally impaired and do not have the sort of autonomy that needs protection (Kittay, 2006). The problem with Kittay's analysis is that it makes a logical jump from personhood being conceptually united with rationality to an inference that those with cognitive disabilities do not have autonomy needing protection. In defense of Kant, one could argue that rationality does still matter for personhood, and persons with cognitive disabilities often have some capacity to reason. Therefore, the rationality that they have, whatever that may be, can still be protected. That is not to say that Kant is right to tie rationality to personhood, but there is still some room for Neo-Kantians to defend Kant against Kittay's critique.

Problems for Neo-Kantians remain, because of their intrinsic commitment of tying rationality with personhood and autonomy. If a Neo-Kantian, like Christine Korsgaard, develops their account to its logical end, presumably they would need to posit a threshold of rationality and personhood (Korsgaard, 1996, 2008). In other words, there is a threshold of rational capacities; and once an organism falls below this threshold, they presumably will lose autonomy and personhood. The problem with positing a threshold has to do with persons who lie just above or just below the threshold. Presumably those lying below the threshold have some capacity to rationalize and should still appropriately be characterized as having autonomy or agency. Further pointed questions can be asked of the threshold theorist: where exactly does the threshold lie? Who decides where the threshold is and on what basis? What capacities lie on the threshold, and count as important to the threshold? Answers to these questions should have some reason guiding them, and should certainly not be arbitrary. Finally, while the capacity to rationalize might have something to do with agency, it still might be presumptuous to suggest that it is the only thing that matters for personhood and the capacity to act.

The Modern philosophers Locke and Kant both develop views about rationality that have implications for those with cognitive disabilities. Locke explicitly asserts that persons with intellectual impairments do not have autonomy, and Kant implies that those with cognitive disabilities stand a very good chance of not being persons -if they exist below a certain threshold of rationality. In particular, Kantian views of agency are not without their problems, and should be either qualified or abandoned due to the implications they may have about the agency and autonomy of persons with cognitive disabilities. However, I don't think they should be wholly abandoned. Rationality matters when determining how one is an agent and how one pursues self-governance. The problem I have presented is with reducing agency and self-governance exclusively to rationality and unjustifiably associating an intrinsic value of persons with the capacity for rationality. Discourses of agency and self-governance should in some respects be broadened to include persons with limited cognitive capacities and they should be more cognitively and neurologically diverse.

1.3. The Industrial Revolution, Eugenics, and Forced Sterilization

During the beginning of the nineteenth century the so-called "Industrial Revolution" introduced new and complicated machinery requiring specific technical and practical skills to operate. During this age, persons with intellectual disabilities were marginalized as a group and perceived as having no social or practical skills to sustain themselves. Consequently, they were perceived as a social burden. By the late nineteenth century, persons that were considered "feeble-minded" were seen as a threat to society because of the way they "propagated their own kind, and hence spread many of society's social ills ." (Atherton, 2007, p. 49) The general fear associated with feeble-mindedness was that it would cause the collapse of society, and the condition was seen as the primary cause of moral vices like prostitution, alcoholism and other

conditions that reduced mental and physical vigor. With many of society's ills blamed on feeble-mindedness, it was inevitable that there would be an effort to control the individuals who lacked proper autonomy or agency. Control of them was needed if society was going to be fit for survival, and the emerging science of eugenics provided the means and justification for this control.

In "Inquiries into human faculty and its development", Sir Francis Galton defines eugenics as a science that improves innate human properties through selective breeding (Galton, 1883). According to Galton, the trait of feeble-mindedness was passed on through family members via a means that was unaffected by the environment. He proposed that through "negative eugenics", one could prevent the procreation of those who were perceived as feeble-minded and socially deviant. In the beginning of the twentieth century, Mendel's laws of heredity were understood as lending support for Galton's proposal and providing the proper conditions for policies based on Social Darwinism. Cognitive disability was now a condition that had profound political and social implications. The condition was intimately tied to social deviancy, and it was assumed that there was a desperate need to resolve the feeble-mindedness "problem". If persons with cognitive disabilities had any sort of capacity for self-governance or agency, then presumably the social need to alleviate the woes of society had to take precedence over respecting this capacity.

In 1904 a Royal Commission was created to investigate the problem of feeble-mindedness and other associated conditions. The Royal Commission advocated state intervention based on policies of negative eugenics in the form of institutionalization. The phrase "negative eugenics" was a term inspired by Galton's work on "positive eugenics". If positive eugenics was a policy meant to encourage the reproduction of those perceived as fit and strong, negative eugenics was a recommendation of how to discourage the propagation of those who were perceived as

undesirable or defective. Galton was the father of both policies, but negative eugenics, in the form of discouraging reproduction of undesirables, was the stronger of the two policies.

Institutionalization was one form of politically controlling the reproduction of persons who were deemed feeble-minded, insane, epileptic, alcoholic or criminal through exclusion from social participation.⁵

Institutionalization proved an ideal environment where an individual's autonomy could be controlled and limited. Not only were those perceived as feeble-minded excluded from social participation through institutionalization, but the men and women who stayed in institutions lived strict and regimented lives. Men and women were segregated and required to do work for the hospital. If they did not conform to the hospital regimen, they were punished (Atherton, 2007, p. 52). This forced segregation of men and women was meant to control the sexual autonomy and agency of the institutionalized guests.

Sexual agency is a particular sort of agency that is associated with deep, personal decisions about whom we have sex with, how we want to have sex, and whether we want to have sex. It also involves decisions about whom to procreate with and whether or not we should or should not have children. When choices about one's sexuality are manipulated or controlled by another party, one's sexual agency is violated. Sexual autonomy is violated when one is raped, forcibly sterilized, coerced to be sterilized because of a genetic impairment, or when one is sexually abused. It might be objected that there are many ways of violating sexual autonomy or agency, and each ought to be treated separately. However, I draw the distinction between sexual

⁵ The last category we typically associate with behavior rather than "traits", but Galton appears to unify the two concepts. In other words, bad behavior was a characteristic of a bad trait, which can be passed on to their offspring. It would not be an intellectual stretch to say that Galton's view on behavior was incredibly fatalistic.

agency and autonomy from other violations of agency and autonomy to note the deep and personal violation that occurs when one's sexual autonomy is compromised by others.

Other forms of sexual agency violation can be found in other eugenics policies which occurred across Europe. Two most notable eugenics policies included the mass genocide in Germany in the 1930s and 1940s, and forced sterilization. The former policy was a violation of sexual agency, because it was intended to cease the spread and propagation of perceived undesirables and permanently eliminate the opportunity for them to have sex and procreate. The forced sterilization policy -presumably understood as the less extreme of the two eugenics policies- was eventually adopted on a global scale. It occurred in two Canadian provinces (Alberta and BC), across the United States, Czechoslovakia, Germany, Japan, India, China, Peru, Russia, Sweden, Switzerland, Uzbekistan and Puerto Rico. However, a closer look at Alberta's sterilization policy reveals that it was not entirely about controlling the procreation of socially perceived undesirables.

1.3.1. A Closer Look at Alberta's Sterilization Act

Alberta's Sexual Sterilization Act was passed in 1928. The following year, a four-member board, headed by the Albertan philosopher John MacEachran, oversaw a process that determined which citizens of Alberta were to be characterized as feeble-minded and prevented from having children. Amongst the overrepresented in the cases of sterilization were persons in minority groups including aboriginals, women, and poor people. This suggests an implicit bias during the process of determining which persons should be sterilized, a bias that specifically targeted minorities (Grekul, 2008, p. 249). The implicit bias of targeting minorities is not surprising, since apparent "scientific" links were made between feeble-mindedness and social problems by so called "experts".

The sociologist Jana Grekul notes that important public figures -most notably middle class women- actively campaigned for sterilization programs to rid the unfit from the culture. Grekul notes that in 1924 the United Farm Women of Alberta worked to gain support for sterilization and attempted to convince the government to pursue racial betterment through weeding out undesirables (Grekul, 2008, p. 250). But why would women be so persistently involved in the abhorrent treatment of their fellow “sisters”? Grekul replies with the following:

The social and political context of the time suggests that women’s involvement in the movement was largely based on their role as protectors of hearth and home. The cult of domesticity placed responsibility for healthy children and functional homes squarely on the shoulders of middle-class women...The middle-class females who worked tirelessly for social reform perceived a marked divide between themselves and their working-class counterparts. (Grekul, 2008, p. 251)

Indeed, it was not just experts and middle-class men who played an important role in the eugenics movement. In Alberta, middle-class women and the gender roles attached to them also played their own unique roles. Once the Act was passed, many middle-class women also participated in the presentation of patients to the board including the social workers who recommended patients for review. Many factors contributed to the diagnosis and sterilization of those deemed feeble-minded including whether one was a part of a minority, who was doing the diagnosing, and who advocated for sterilization legislation.

Narrow gender and sexual norms for women also played important roles in the Alberta sterilization procedures. A detailed write-up of each patient was provided to the eugenics board and part of the write up included one’s sexual history. A reported 32 percent of women in the 1930s mentioned “promiscuous behavior” in the write ups including patients who were described as having a “history of sex interest and promiscuity,” and, “admitting sexual indiscretion between

four or five boys”. Another patient was described as having “no sexual control at all and is a menace wherever she is placed.” (Grekul, 2008, p. 259) If women were perceived as not conforming to particular sexual norms about how many persons one could have sex with and norms about having sex within the confines of marriage, then they were deemed promiscuous. Subsequently, this promiscuity was considered a reason for sterilization.

Sexual norms about promiscuity were not as strict for men as they were for women. The nature of promiscuity differed for men, which included sexual acts like having sex with a prostitute.⁶ It would appear that what counted as sexual promiscuity amongst men occurred on the more extreme end of a sexual deviancies spectrum. Comparably, women were promiscuous if they had sex with multiple males outside of marriage. Not surprisingly, there was a large disparity between how many recorded cases involved promiscuity. Grekul writes, “By the 1950s, there are only three cases of recorded promiscuity for males while promiscuity emerges as a theme in 26 percent of female cases.” (Grekul, 2008, p. 259)

Consent norms also played a role in sterilization during the implementation of Alberta’s Sterilization Act. While in the beginning the act of consent was necessary before sterilization, an amendment in 1937 made consent unnecessary (Grekul, 2008, p. 255). Consent was not sought in cases where a person had a diagnosis of being mentally defective and could not make their own decisions. The amendment did not mean that consent was never sought, but resulted in a decrease in cases of sterilization where consent was required. Interestingly, women were more likely than men to have consented to the sterilization, indicating that more women than men were recommended to be sterilized because they violated proper norms of feminine behavior or were perceived as not suitable mothers. In other words, women were not mentally abnormal; they were

⁶ It can be pointed out that this still has not changed in North America.

more normatively abnormal than men, which made them disruptive to society's moral order. The women that were sterilized were perceived as violating certain moral and/or social norms, not necessarily as mentally incompetent.

It is less clear that the women who were sterilized actually consented in cases where it was reported that they did, since it is entirely possible that they were coerced in some way. The first way that the women could have been coerced was by being confronted with the cultural and social pressure to be reproductively responsible. The second way that women could have been coerced was by being directly pressured by professionals overseeing the sterilization movement, perhaps by convincing individual women that they were incapable of being good parents. Either possibility of coercion suggests that there were pressing questions about whether the women who were reported to consent did so voluntarily.

The lessons one can take away from the forced sterilization movement are numerous. The sexual agency of men and women were undoubtedly compromised. However, there are a number of causal links associated with what caused the mass disregard of the autonomy of persons that were perceived as feeble-minded. Class, gender norms, race, sexual norms, experts diagnosing those with feeble-mindedness and legislation of consent all played crucial roles in the myriad of elements that factored into the compulsory sterilization of undesirable Alberta citizens. Furthermore, the elements that constrained and violated agency in this case were not necessarily about individuals exercising individual capacities to make decisions. Instead, the ability to execute intentional actions also depended on several external elements. Furthermore, one can almost hear the faint whispers of the ancient past wherein persons with perceived intellectual disabilities were manipulated to conform to social expectations. The sterilization movements - like the one in Alberta - represent one of the most penetrating examples of violating the agency and autonomy of persons with perceived intellectual impairments.

1.4. The Contemporary Scene and Beyond

It was during the mid-to-late 1900s that cognitive disability began to emerge as a subject for philosophical and ethical inquiry (Carlson & Kittay, 2010; Kuhse & Singer, 1986).

Philosophers began to question traditional assumptions regarding the moral status of individuals with cognitive impairments. However, the dominant assumptions about agency appeared to remain. Persons with cognitive disabilities had diminished autonomy and agency because of their diminished capacity to reason. I additionally suspect that during this period the threshold view of rationality and autonomy was also in place, wherein if a person was considered below a threshold of rationality, they could no longer make their own decisions.

The contemporary philosophical scene has somewhat changed. Philosophers have taken cognitive disability as a challenge to some dominant assumptions about agency and autonomy and use the existence and experiences of persons with cognitive disabilities as a starting point to launch discussions regarding agency (Francis & Silvers, 2010; Nelson, 2010; Shoemaker, 2010; Wikler, 2010). I will address the points these philosophers make and explain in more detail where I disagree with them in the next chapter.

While some philosophers have addressed cognitive disability in their philosophical accounts of agency, surprisingly few have paid any attention to the existence and experiences of *persons* with cognitive disabilities. Philosophers generally seem more interested in developing accounts of “normal” human agency and decision making, rather than taking account of those who do not meet particular standards of rationality. In other words, agency still seems to be understood as some sort of capacity; but the focus is on understanding certain mechanisms associated with an individual’s capacity to perform particular actions. If one has a diminished capacity to perform certain actions, then there is a very real chance that they may not be agents.

Therefore, philosophy of the past and some contemporary philosophy reflect an attitude towards those with cognitive disabilities that implies a diminished agency and diminished capacity to be autonomous. For the most part, philosophical reflection has been about how persons with cognitive disabilities fail to be agents, and there has been very little reflection on how persons with cognitive disabilities can be agents and fully autonomous. The next chapters cast a critical eye on this tradition and present an account of how persons with cognitive disabilities can be agents and autonomous.

So how does one respect and regard the agency and autonomy of persons with cognitive disabilities? First, learning from our historical past, we should regard the agency of persons with cognitive disability in terms of a broader framework that reaches beyond individuals exercising their rational and moral capacities, and acknowledge the larger social context in which persons with cognitive disabilities exist. Many persons with cognitive disabilities still have some capacity to formulate a conception of the good and some capacity for rational plans of action, and these capacities ought to be respected. Simultaneously, many persons with cognitive disabilities also exist within a care environment with other agents who take over for faculties that might have been lost because of their impairment, and therefore the exercise of their agency involves the integration of caregivers. In other words, the caregivers supplement and enhance, rather than supplant their agency. Caregivers may be understood as facilitating or promoting the capacity for rationality and agency the person has. Shared or helping agency should be acknowledged and incorporated into the general understanding of the agency of persons with cognitive disabilities. Furthermore, persons with cognitive disabilities may be vulnerable to manipulation, and such manipulation should be regarded as morally repugnant because it does not respect the particular capacities that the person has, including the person's right to be respected and not be harmed. If violation of the capacity to make decisions is harmful because it violates agency, and if

manipulation violates this capacity, then manipulation is part of a violation of one's agency. Prohibiting such manipulation is in order to protect the cognitively disabled from future manipulations and violations of agency. Finally, it may be necessary to either abandon or qualify threshold views that unite rationality and agency, because such views do not acknowledge the larger social context and environments in which persons with cognitive disabilities exist. Threshold views fail to be cognitively diverse and fail to include external elements that are relevant to decision making. Agency is far more than intentions of individual persons and their special capacities. I will develop and defend this broader account of cognitive disability and agency in future chapters.

More generally, one of the implications of my account is acknowledging the importance of incorporating cognitive disability into discussions of normative ethics. This is necessary in order to develop a more robust account of agency that is inclusive of persons with cognitive and neurological disabilities. Particular attention needs to be paid to how persons with these disabilities can be agents and autonomous and what goes into promoting or limiting their agency. The next chapters will be my effort to develop an account of how said persons can be agents and how they can be autonomous, to move beyond the troubling philosophical past that I have presented.

Chapter 2: Agency and Cognitive Disability: Agency within a Social Environment

The philosophical tradition tends to ignore, or at least does not adequately appreciate, the way social environments can restrict or expand agency. Often the agency is narrowly equated with individual organisms' capacity to exercise rational thought. There are flaws in any theory of agency that restricts it in this way, because it does not acknowledge how persons with cognitive disabilities exist within a social context, wherein their cognitive capacities can be improved or impaired by environmental features. In other words, cognitively disabled persons exist in environments where others –typically care givers– can potentially take over or compensate for rational capacities that they lack or have in impaired forms. There is a potential for other agents to assist cognitively disabled persons in forming and thinking about decisions, even when an individual lacks certain capacities that allow one to make decisions alone. It is important to acknowledge how a person is an agent, because if one is traditionally conceived of as always consenting, not capable of consenting, or not capable of being an agent, then there is a risk that a person will not be able to rightfully claim that their autonomy has been violated. There would be little to no legal or political means that one could take when a cognitively disabled person's autonomy has, in fact, been violated. To avoid this possibility, laws and policies should be formulated, implemented and enforced to broaden the scope of who is perceived as capable of making decisions, and who is capable of giving and withdrawing consent to medical interventions or receiving assistance for daily life tasks. Consent refers to the act of agreeing with or giving approval of actions or activities that impact one's self. Acknowledging the broadened sense of agency expands the scope of who is seen as being able to make decisions and who can give and withdraw consent.

This chapter focuses on the social environment in which persons with cognitive disabilities exist, and some contemporary philosophical literature that accounts for cognitive disability in their deliberations about agency. I begin with a discussion of paternalism, and when it might be appropriate to deny certain decision making possibilities of cognitively disabled individuals. Secondly, I present and critically appropriate a theory of mind that could provide an ontological framework for understanding how persons with cognitive disabilities could make decisions in their social world. According to this theory of mind, one's mind and cognition extend into the world. More specifically, the theory implies that one's mind extends into the world to include iPhones, notebooks, and other persons. Particular attention will be paid to where I depart from these contemporary philosophical accounts.

2.1. A Brief Discussion on the Disorders that are Discussed

First I present a brief introduction to possible disorders that affect the way one makes decisions and the disorders that affect one's agency. For the sake of clarity, I will refer to specific conditions when such information is particularly relevant. But in many cases, my claims can be generalized to all or most of the conditions I present. My primary goal is to provide a general account for as many cognitive disabilities as possible. At the same time, even when a claim can be generalized to other disorders, it is still possible that the claim may not apply to all of them. Some disorders, because of the nature of the impairment, may count as an exception to one of the claims I make. Acknowledging the nuances and complexities associated with specific impairments can make the task of giving a general account of cognitive disability more difficult. However, while acknowledging the myriad of complexities around these issues, something accurate, plausible and philosophically interesting can still be said about the various groupings I consider.

The specific conditions I will be discussing are autism, severe cases of cerebral palsy, Down syndrome, Alzheimer's disease, and intellectual and developmental disabilities (IDD). Autism, Down syndrome and cerebral palsy are neurodevelopmental disorders which occur because of an inhibition in the growth or development of the brain or central nervous system. Often, these disorders occur in infancy or childhood. More specifically, the group of disorders classified as "neurodevelopmental" denotes disorders of brain functions and brain systems that affect learning, memory, and emotions. In contrast, Alzheimer's disease and other forms of dementia are neurodegenerative, and occur when there is progressive loss of brain systems and structures due to the death of cells and neurons. Intellectual disabilities include both neurodegenerative disorders and neurodevelopment disorders. They can additionally include persons who have an intelligence quotient (IQ) lower than 70, along with persons with cognitive impairments who have a normal IQ, yet display the forgetfulness, difficulty concentrating and confusion that typically accompany brain injuries.

2.2. Agency and Paternalism

The social environment of persons with cognitive disabilities includes other persons with normal abilities. Correlated with existing in a society that consists of multiple cognitive abilities, there is a chance that one's social liberties can be restricted by an elite group, such as persons with statistically normal cognitive functionality restricting the social liberties of those with cognitive disabilities. A group of individuals whose social liberties can be restricted includes those who understand some of the joys and challenges of life, have the capacity for emotions, have normal emotional intelligence for their age, yet have an IQ below the cusp of normalcy. Upon reaching adulthood, cognitively impaired individuals are often denied certain decision-making powers that are afforded persons with normal cognitive abilities. In such cases,

cognitively impaired individuals are expected to submit to the guidance of more competent persons or authorities when deciding large life decisions like whether to have children, whether to live alone, consent to risky surgery or consent to financial contracts. The social environment that the cognitively disabled live in can severely restrict and constrain the exercise of their actions.⁷ For example, consider when a caregiver wrongly assumes that a particular cognitively disabled person may not be able to choose what to eat or when to eat it, so they paternalistically choose for them. In this case, the capacities of the cognitively disabled person are unacknowledged and controlled by another party, and their agency is severely restricted or constrained. Moreover, this attitude is socially structured, because it is often assumed that persons with cognitive abilities cannot make decisions for themselves, and this assumption is socially enforced and unreflectively accepted.

It appears that intellectual superiority justifies restricting the social liberties of cognitively disabled individuals, as opposed to restricting liberties on the grounds that cognitively disabled persons are a danger to themselves and to others. In “Cognitive Disability, Paternalism and The Global Burden of Disease”, Daniel Wikler writes, “[i]n the liberal tradition the expectation of doing harm to oneself is certainly part of any strong argument for a paternalistic denial of liberties..[however] an expectation is not itself sufficient to make a case for restrictions.” (Wikler, 2010, p. 184) Wikler plausibly argues that persons with normal intelligence can still pose a risk to themselves and others, yet we still hold freedom to choose and freedom to fail as a central liberal tenet. The fact that one may not act in a way that maximizes their well being does not, in itself, provide a sufficient basis for restricting liberty. Persons with cognitive disabilities,

⁷ With that being said, the right sort of environment may also be positive, and can improve one’s agency. Indeed, whether an environment restricts or enhances one’s autonomy is highly contingent and can be subject to change.

so the argument goes, may not have the capacity to understand associated risks regarding the consequences of decisions, weigh possible alternatives, or grasp concepts associated with responsibility for one's actions. At the same time, the capacity to understand associated risks regarding the consequences of decisions, weigh possible alternatives, or grasp concepts associated with responsibility comes in degrees. So the restriction of liberties is not an all-or-nothing condition. The reason to restrict certain social liberties, to any degree, directly relates to one's intellectual capacities, and whether the intellectual capacities associated with decision making have been compromised. If one cannot understand what is at stake when choosing and acting, weigh possible alternatives, or grasp concepts associated with responsibility for one's actions, then one might argue that there is reason to restrict the freedom of that agent.

The capacities relevant to agency come in varying degrees, and the degrees of severity of impairment appear to be relative to the surrounding social context in which one is embedded.⁸ Consider, for example, a society where cognitive enhancement is possible. The society consists primarily of persons with cognitive enhancement which allows them to perform intellectual tasks well above the level of the minority. Consider further that the social structures which correspond to the cognitive abilities of the majority are created to cater to individuals with cognitive enhancements. Therefore, the decisions that are made to fulfill daily life tasks in this society

⁸ A relevant distinction can be made between having a cognitive impairment because of a neurological condition, and a social context that restricts the exercise of a capacity an individual has. That being said, it is not entirely clear that one can easily tease out the distinction between an impairment based on neurological impairment, and a restriction based on social context (Altman, 2011) (Edwards, 1997). Moreover, the social context can exacerbate or ameliorate impairment. Consider the impairment where a person has delusions that they are the star of a reality TV show, and their daily tasks are broadcasted to a national audience. Such a delusion would not be possible without reality TV existing in the social environment.

include complex calculations and ruminations. Driving may be a challenging cognitive task, medical decisions would assume a high degree of intellectual competence, and financial decisions may require a high degree of computational ability without an assisted device (since calculators may not be necessary for the cognitively enhanced). In this society, those who would be counted as intellectually deficient would most likely include those without enhancements in addition to those who classify, in our society, as cognitively disabled. The severity of a disability, therefore, is a context-sensitive category that is dependent on one's social surroundings, and with whom one occupies the social space, or where one lies on a continuum in comparison to others. One cannot understand "severely cognitively disabled" or "severely intellectually challenged" without reference to those who are moderately disabled or not disabled at all. This does not mean that classification of the category of cognitive disability is necessarily a relative category; rather, the degree and severity to which one is intellectually deficient must be understood in comparison to other social members or other members on a continuum of cognitive ability or disability.

In the society described in the thought experiment, should the social liberties of the unenhanced be restricted? A plausible argument could be presented that the liberties of persons that are unenhanced in the society should be restricted because, in comparison to the rest of society, they are intellectually deficient. However, it is not entirely clear that the unenhanced really lack the necessary intellectual capacity to complete certain decision-making tasks. While some tasks may require the assistance of the cognitively enhanced, it is not clear that all tasks require such assistance. Part of the reason that one would restrict the social liberties of the cognitively disabled must be because they lack the intellectual capacities necessary to fulfill a decision-making task. Wikler argues that in such cases one can save the "paternalistic restriction of the cognitively disabled.. [and] [t]his requires that 'full' mental capacity be understood as a 'range property,' one which is possessed in equal measure by all who possess it." (Wikler, 2010,

p. 189) Wikler presents a threshold view of cognitive disability wherein those above a certain threshold have the necessary cognitive abilities to make decisions, and every person above the threshold is equally endowed with social liberties. Comparatively, those below the threshold lack necessary cognitive capacities and therefore they may not be endowed with certain social liberties. One might be tempted to interpret Wikler as holding an “all-or-nothing” view of cognitive capacities and social liberties, but it is not clear that the threshold is a firm or fuzzy boundary. Indeed, the latter seems to be a more accurate reflection of reality. Wikler further argues that mental capacities ought to be seen as a matter of competence in meeting a challenge (Wikler, 2010, p. 189). One may meet certain challenges, and an individual may be as competent at performing some tasks as others, even if she or he has less intelligence than another. Furthermore, additional intellectual prowess could just be simply an “unused surplus.” (Wikler, 2010, p. 190)

Wikler argues that there are cases when an individual may lack certain intellectual capacities, and in some of these cases it seems necessary to treat them paternalistically. Indeed, Wikler wants to maintain that there are cases when paternalism is an appropriate response towards a cognitively disabled individual. In such cases, persons with cognitive disabilities are expected to submit to the intellectual elite to make decisions on their behalf.⁹ However, Wikler ignores certain social dynamics that make his suggestion less tenable. A more nuanced view about paternalism is necessary.

Wikler’s suggestion seems to presuppose an overly antagonistic social dynamic. The social dynamic in question is composed of persons with normal intellectual capacities who are, in

⁹ Although Wikler does not use the term “elite”, he does appear to suggest that certain citizens are granted power because of what they know or their ability to exercise certain intellectual capacities.

some way, opposed to those lacking certain intellectual capacities. If a person has some intellectual powers, yet still exists below a threshold regarding these powers, their decision-making powers could be restricted and controlled by the other party. However, persons with normal intellectual capacities can still assist persons with less intellectual capacities to make decisions for themselves. It need not be the case that individuals that are adequately endowed with intellectual gifts wholly take over the relevant tasks for the other. Rather, they only take over to the degree that is required to carry out the desires and intentions of the cognitively disabled. With this point in mind, while social dynamics can restrict the social liberties of persons with cognitive disabilities, they can also stand in a correct position to improve the social liberties of persons with cognitive disabilities and help them make decisions for themselves.

Ideally, normal medical decisions can be made with this helping social dynamic in mind. A patient seeks the opinion of a doctor who has the necessary knowledge that the patient requires, but lacks to some degree. The doctor advises the patient about what clinical options are available for the patient. In the end, the patient consents to the treatment and is the one who ultimately makes the decision. The doctor and patient ideally have an interdependent relationship wherein the patient has an integral and necessary role in making their own medical decisions. Under this view, the social dynamic between them need not be interpreted as antagonistic. Instead it can be interpreted as helping the agent make self-governing decisions and thus promoting autonomy.¹⁰

Furthermore, Wikler's suggestion presupposes a problematic threshold view about cognitive disability. Recall that according to Wikler's threshold view, persons below a certain

¹⁰ For a more detailed analysis of patient-doctor relationship see (Emanuel & Emanuel, 1992). While there are multiple schemas available for understanding the relationship between the patient and doctor, I argue that physicians are not usually understood nor should they be understood as paternalistic overseers of the patient's health.

intellectual threshold should not be afforded certain social liberties because they lack critical intellectual capacities. Wikler writes, “[t]hose lacking enough intelligence for the task will be incompetent to perform it.” (Wikler, 2010, p. 189) But, the actual social dynamics of cognitively disabled persons are far more complicated. Consider an individual who functions just below the threshold of having enough intelligence to complete a task on their own. This individual will presumably have some relevant intellectual capacities. Yet there is no structure in place, under Wikler’s view, to suggest that a person’s decision making can be improved by another agent. In other words, there is no theoretical or practical structure in place to suggest that another person can enter into another’s social sphere and help an individual perform and accomplish an intellectual task. That is not to say that Wikler’s proposed threshold cannot be useful in assessing whether a person can perform an intellectual task *alone*. Rather, he fails to adequately acknowledge the social world in which a person with a cognitive disability lives and acts. If one were to maintain a threshold view, then that threshold ought to at least include the person’s social world. The threshold would be influenced by social structures and other features of the social world.

Another alternative option for maintaining the threshold view is to posit a second threshold in accordance to when a person can receive help and when they cannot. As I previously stated, the threshold view may be useful when we are trying to determine whether a person can make decisions alone. So, rather than incorporating the social world into a single threshold, a second threshold could be posited for when a person can be helped or hindered by the social world. The first threshold is based on whether a person can make decisions alone; the second threshold is based on whether a person can make decisions with another agent. Some conditions, such as severe forms of autism, may vacillate up and down on this second threshold, because part of the nature of the impairment may be associated with interactions with the social world, and the

inability to respond appropriately to social cues. Indeed, for some disorders, one can fail to respond to social cues yet be able to communicate one's intentions and articulate how one may need help. This hinders the degree of help others can offer, if helping, to some degree, requires responses to social cues, communication of intentions, and articulation of how others can help.

When one takes into account the possibility of an agent being helped by another, it creates problems for overly simplistic threshold views of agency. An overly simplistic threshold view is one that is too narrow and misses some critical aspects of agency. Wikler's threshold view is overly simplistic because it only acknowledges the capacity for the social context to constrain and limit an agent. He downplays the possibility of one's social environment to enhance the capacity to form decisions and carry out actions. Wikler additionally and erroneously understands agency exclusively in terms of a threshold wherein agents exercise individual intellectual capacities. An account of agency needs to include other agents helping cognitively disabled agents exercise intellectual capacities. It needs to include other agents helping other agents carry out actions that may be too difficult to carry out on one's own. Since Wikler does not adequately take into consideration the social dynamics where an agent is helped by another, his account of paternalism is unsatisfactory.

2.3. Extended Minds, Extended Agency?

In the previous section, I emphasized the point that an account of agency for cognitively disabled persons needs to include the possibility of other agents helping agents exercise intellectual capacities. I lament that to ignore the appropriate social dynamics on which agency depends is to discount a particular mode that persons can be responded to and respected as agents. One promising way to account for the social dynamics of agency in care-giving relationships is to borrow from extended mind theories that couple the mind with the

environment in which it is embedded. The idea behind such theories is to match one's consciousness or cognition with items that exist beyond the brain, and these theorists argue that the mind includes items beyond the mere organic functioning of one's brain. In this way, the mind is understood as extending into the world. It is additionally notable, for our purposes, that a central character of the thought experiments for extended mind theories is a person afflicted with Alzheimer's disease who uses a notepad to help him remember things (Clark & Chalmers, 1998). Extended cognition theories suggest that cognition is much more than mere functioning of certain capacities of the brain, but extends beyond the brain to include iPhones, notepads, and other items featured in our environment.

One can broaden the extended mind theory to include other agents in the content of one's mental states. The idea behind this theory is that when exercising certain cognitive capacities dedicated to decision making, one's own agency can include other agents. If cognition includes other items featured in our environment and cognition supervenes on a wider range of factors than one's own neural processes, then there does not seem to be any principled reason to deny that cognition can also include other agents. If cognition includes other agents, then in some cases cognition can extend into the social world. The idea of extended agency is featured in the work of Andy Clark, who presents and defends the theory. It is also applied to disability related issues in the work of James Nelson and in the joint work of Leslie Francis and Anita Silvers.

The theory of extended mind is primarily found in the pioneering works on the subject, started by David Chalmers and Andy Clark. One of the central ways that Clark and Chalmers flesh out their theory is via a thought experiment about a man who suffers from a moderately advanced case of Alzheimer's called "Otto" (Clark & Chalmers, 1998). Otto enjoys the Museum of Modern Art, but cannot remember where the museum is located without the utilization of a notebook that contains the directions he requires. Otto has a friend named Inga who can

remember the museum's location without a notebook. According to Clark and Chalmers, the different modes of performance of Otto and Inga do not matter. After all, Otto has an accurate belief about the location of the museum. Although his way of remembering how to get to the destination differs from Inga, his way of remembering is reliable as long as he has access to it. To separate Ingrid and Otto is to inappropriately privilege the brain or collections of neurons. Although it is not explicitly mentioned by Clark, this assumes that Otto retains some form of memory mediated by some degree of brain function.

In "The Extended Mind" Clark and Chalmers ask, "[w]here does the mind stop and the rest of the world begin?" (Clark & Chalmers, 2010, p. 27) The idea behind the extended mind is that the environment plays an active role in the content of cognitive processes, and it does so through causal coupling. Causal coupling refers to the idea that there is a strong interaction between internal and external systems, and modulation of one system can change the other. Referring to causal coupling, Clark and Chalmers state, "[b]ecause they [external objects and systems] are coupled with the human organism, they have a direct impact on the organism and on its behavior." (Clark & Chalmers, 1998, p. 9) The so called "parity principle" is an additional concept necessary to the extended mind theory. According to the parity principle, external elements that are causally coupled with cognitive systems associated with the brain partly constitute the mental content. Referring to the case of Otto, the notebook plays an active role and is coupled with Otto's mind. According to the parity principle, what occurs in Otto's notebook is part of Otto's cognitive system. The mind, therefore, extends into the external environment, and mental contents can be external to the person and his or her brain.

The extended mind thesis is comparable to externalist theories about meaning or so called "semantic externalism". According to semantic externalism, the meaning and reference of the words we use are not solely determined by an internal physical state, or the ideas we associate

with them. Hilary Putnam famously argued for semantic externalism with his “Twin Earth” thought experiment (Putnam, 1975). Imagine that in 1750, there was a remote planet called “Twin Earth” which is exactly like Earth but contains no water (H₂O). Rather than H₂O, twin earth has a similar substance to water but has a different chemical compound, XYZ. The macro properties of XYZ are just like water: it tastes like water, nourishes the body like water, is found in rivers and oceans, and citizens of twin earth put their tea bags in it at tea time. In 1750, nobody on Earth or Twin Earth could distinguish between water and XYZ. It is argued that a person on Earth in 1750 who used “water” would refer to H₂O and not XYZ, even though he or she did not know that water was H₂O. Similarly, if he pointed to XYZ and said “this chemical substance is water”, the utterance would be false. The meaning of the word, according to semantic externalism, depends, at least in part, on the external environment the linguistic user is embedded in.

The distinction that Clark and Chalmers make between semantic externalism and extended mind theories is that extended mind theories are an *active* version of externalism. The externalism Clark and Chalmers defend extends beyond content to acts and functions. Clark and Chalmers say, “[o]thers are impressed by arguments suggesting that the meaning of our words ‘just ain’t in the head,’ and hold that this externalism about meaning carries over into externalism about mind.” (Clark & Chalmers, 2010, p. 27) Therefore, Clark and Chalmers propose that if some process plays a role in the cognition of agents such that the process could go on inside the cognitive agent, we should count it as part of her mind, regardless of whether the process occurs in the brain or in the environment.

This theory has some implications for persons with cognitive disabilities, since the external environment that the person is embedded in could be counted as part of their mind. Otto, for example, becomes cognitively enabled through interacting with his notebook. Otto’s

notebook is part of his mind and himself rather than merely a simple piece of paper with etchings. In “Alzheimer’s Disease and Socially Extended Mentation”, James Nelson explores how extended theories of the mind might bear on conditions and Alzheimer’s disease, particularly when it comes to proxy decision makers. First, Nelson claims that the mind extends into both artifacts and people. He says, “externalism allows, at least in principle, that our minds may extend not only into artifacts but into other people as well...Some of my memories or my evaluative beliefs may have been stored not in a notebook or an iPhone but in another person.” (Nelson, 2010, p. 235) Presumably Nelson wants to imply that a memory could still be mine, but stored in another person’s brain to be utilized later. But when are memories mine and when do they belong to the other person? Or, alternatively, are they both mine and the other person’s at the same time? Sadly Nelson leaves these pressing questions unanswered. Naomi Scheman similarly argues that mental states encompass and supervene on other people (Scheman, 1993). Second, it is also possible, according to Nelson, for demented persons to be assisted by their care givers or proxy decision makers. In such cases, Nelson states, “a now-demented person may be autonomously forming or consolidating new evaluative beliefs that constitute respect-worthy responses to situations unanticipated earlier in her predementia life.” (Nelson, 2010) There is a possibility, according to Nelson, that other agents constitute one’s own agency when they are being utilized as proxy decision makers or caregivers.

Leslie Francis and Anita Silvers appear to share Nelson’s intuition about other agents constituting a part of one’s own agency. They argue that people in general cooperate with each other in constructing their conception of the good and depend on each other in important ways in retaining this conception. Francis and Silvers present a metaphysical theory for how persons with disabilities collaborate with a trustee to build conceptions of the good, by borrowing from a metaphysical theory of how persons use prosthetic body parts. According to the metaphysics of

prosthetics, a prosthetic arm or leg “executes some of the functions of a missing fleshly one without being confused with or supplanting the usual fleshly limb.” (Francis & Silvers, 2010, p. 247) Like a prosthetic limb, a trustee may not necessarily supplant the ideas or beliefs of the cognitively disabled individual. More importantly, Francis and Silvers argue that one usually attributes the functioning of the prosthetics to the agent using them, and not a metal foot who does the walking (Francis & Silvers, 2010, p. 247). If a person were to utilize a prosthetic limb, the limb compensates for the lack of fleshly limb and gives its wearer the capacity to roll, walk or run. Comparatively, a collaborator would compensate for the cognitive deficits of the disabled person, to provide a capacity that they would otherwise lack or enhance a capacity they have to a limited degree. To utilize the extended mind terminology, the prosthetic device is coupled with the agent, and the prosthetic device becomes a part of the individual’s body. The identification of the person with the device would presumably be influenced by proprioceptive and somatosensory feedback between the device and the person’s brain. There are a few ethical worries, but ideally a trustee assists thinking by functioning as a prosthesis, to amplify the functionality of the individual, rather than being used as a separate tool. Francis and Silvers suggest that one should proceed with caution “to safeguard against substituting the assistant’s standpoint for the person’s own.” (Francis & Silvers, 2010, p. 249) By utilizing the metaphysical theory of prosthesis, I take it that Francis and Silvers assume some sort of extended mind theory. In other words, I take them to be arguing that when a person utilizes a collaborator, the mind extends to the trustee, so the trustee and the capacities granted by the trustee become part of the agent.

A recent neurological study corroborates Francis and Silver’s intuitions about a prosthetic limb actually functioning as a part of the agent. According to a study by Mariella Pazzaglia and colleagues, the human brain learns to treat a prosthetic as a substitute for a non-working body part (Pazzaglia, Galli, Scivoletto, & Molinary, 2013). The researchers discovered that

wheelchair-bound participants with spinal cord injuries perceived their wheelchair as part of their body (Pazzaglia, et al., 2013). Their body's edge was perceived as flexible, and this association was particularly strong for patients who retained upper body movement (Pazzaglia, et al., 2013). To the brain, the prosthetic limb or device becomes a substitute for the affected body. Pazzaglia states:

[T]he tool did not become an extension of the immobile limbs; rather, it became an actual tangible substitution of the functionality of the affected body part. These findings suggest that the brain can incorporate relevant artificial tools into the body schema via the natural process of continuously updating bodily signals. The ability to embody new essential objects extends the potentiality of physically impaired persons and can be used for their rehabilitation. (Pazzaglia, et al., 2013)

According to Pazzaglia, the human brain literally treats prosthetic devices, including wheelchairs, as a functional, tangible part of the body. This finding corroborates Chalmers and Clark's intuition that the mind could extend into non-organic objects in one's environment, because -assuming the brain takes one's body as part the self- the brain appears to treat inorganic, environmental elements, as part of the self too.

2.3.1. Limitations of the Extended Mind Theory and Extended Agency Theory

There are limitations to the extended proxy-decision making theory. A problematic case may be presented wherein an agent, with the help of a proxy-decision maker, forms inconsistent beliefs, which also may be a part of one's mind. When one considers this problematic case, it can involve some complicated ethical decisions about which beliefs one may ethically privilege. Regarding problematic cases of inconsistent beliefs, Nelson states, "[s]orting out how to adjudicate the conflicting implications of those beliefs for practice will, of course, often require

the most careful judgment –and in selecting judges, we would do well to bear in mind that we may have realtime access to some of the very same deliberative resources by which those undergoing disease habitually achieved and sustained mature values, and sorted out their tangled practical consequences.” (Nelson, 2010, p. 235) However, Nelson’s worry does not imply that extended proxy-decision making is false or fails to consider the person’s best interest; nor does his worry make the theory untenable. He merely points to some ethical complexities that one should keep in mind when applying extended mind theories in contexts that include a proxy-decision maker.

A more pressing concern is presented by Fred Adams and Ken Aizawa in “Defending the Bounds of Cognition”. Adams and Aizawa argue that extended mind theorists commit the coupling-constitution fallacy by inappropriately making “an object cognitive when it is connected to a cognitive agent.” (Adams & Aizawa, 2010, p. 67) Clark and Chalmers commit the coupling-constitution fallacy by coupling Otto with his notebook, then inferring that the notebook constitutes part of his memory system. However, Adams and Aizawa point out, “coupling relations are distinct from constitutive relations, and the fact that object or process X is coupled to object or process Y does not entail that X is part of Y.” (Adams & Aizawa, 2010) It is argued that extended mind theories fail because there is no distinction between what the mind and cognition causally depend on and what properly constitutes the mind or cognition. While one might agree that the mind depends on a causal coupling relationship between the brain and the environment, it is an entirely different matter to assert that the resources one uses form part of the larger system that cognizes. Therefore, Adams and Aizawa conclude that extended mind theories commit a fallacy, and they deny that the mind extends into the world.

Drawing on similar intuitions of Adams and Aizawa, another objection against extended mind theory is presented by Kim Sterelny, who draws an analogy between unconscious or

conscious systems and the digestive system. Sterelny notes that our digestion is supported in pervasive ways and depends on technological advances to cook and ingest food, which allows us to extract more nutritional value. Yet we are not tempted to suggest that the digestive system extends into the world. Sterelny says,

We have engineered our gustatory niche; we have transformed both our food sources and the process of eating itself. Our under-powered jaws, short gut, small teeth and mouth fit our niche because we eat soft, rich and easily digested food. Our digestive system is environmentally scaffolded. But is my soup pot, my food processor and my fine collection of choppers part of my digestive system? As far as I know, no one has defended an extended stomach hypothesis, treating routine kitchen equipment as part of an agent's digestive system. (Sterelny, 2010)

Sterelny presents a less metaphysically presumptuous view than the extended mind theory and argues that the mind is environmentally scaffolded or supported by the environment. Although Sterelny does not argue that extended mind theories are false, he does present some pressing concerns for the extended mind theory through his analogy between the mind and the human digestive system and offers a more plausible option for understanding shared and helped agency than extended mind theories.

Recall that Francis and Silvers utilize metaphors about the usage of a prosthetic limbs and the usage of a trustee. There seemed to be corroborating neurological evidence that the brain treats prosthetic devices as if it were part of the body; but there are limitations to this metaphor. While it might be plausible that certain inorganic objects in the environment constitute part of one's body or self, it is less obvious that the brain treats other people as a similar part of oneself. Indeed, it seems more plausible to assume that care givers and trustees are not like a prosthetic limb, because another person has subjectivity, cognitive flaws, well-being, and a different mind.

A person can't manipulate another person in the same way that person can manipulate a prosthetic device. Indeed, the brain even represents what other agents are thinking and doing, and this information is utilized to negotiate the social world and co-operate with others. Therefore, the corroborating neurological evidence may not extend to other agents. Furthermore, just because a brain treats objects as if it were part of one's own body does not imply that a prosthetic device, in fact, constitutes part of the body. In other words, the brain *thinks* that the prosthetic device is part of its body, but that does not make it so.

Finally, additional worries about the nature of Alzheimer's might complicate whether the mind or one's agency can be extended. Recall that Otto writes in his notebook and uses it to find his way to the museum. Alzheimer's is a progressive disorder that, at a certain point, impedes one's capacity to retrieve memories and construct meaning from those memories. In other words, at some point the notebook would be useless for Otto, because he could not properly contextualize the information in the notebook. Furthermore, Alzheimer's affects one's capacity to use and interpret language. It is, in part, a linguistic disorder, which hinders an agent's capacity to use language in a notebook, and hinders one's ability to negotiate in the social world in a way that communicates one's wants, needs, or desires. This suggests that the extended mind has its limitations, and how the brain functions plays a crucial role in how extended the mind can actually be, if it is extended at all.

One should be skeptical about extended theories of agency where one's own agency extends to other agents, even if the mind is extended to inorganic objects. Recall that according to extended agency theories, other agents constitute part of one's mind. It appeared to be a promising endeavor to consider care givers and proxy-decision makers as part of a cognitively disabled individual. But, if one were to consider trustees or proxy-decision makers as part of the agency of a cognitively disabled individual, one may run the risk of losing the caregiver's

autonomy. It is appropriate, at least sometimes, to consider an agent as separate from the person they are helping or assisting. When one violates another's autonomy, it is a strong example of when an agent is not extended to another agent. However, even when one is being assisted to make decisions, the helper still has their own subjectivity, preferences, weaknesses, desires, goals and well-being. To say that the helper is "extended" to the person they are assisting, could run the risk of ignoring a caregiver's well-being, desires, and goals at the expense of the cognitively disabled person's well-being, desires and goals. This assumption could also undermine the agency of the cognitively disabled person. This shows that combining the extended mind hypothesis with paternalism can have harmful results for the cognitively disabled person, because it fails to appreciate his or her own distinctive needs and interests. This worry is particularly relevant in contexts where two individuals' well-being, desires and goals conflict. In such cases, in my experience, one needs to take into account both individuals' autonomy to negotiate a course of action that is in the best interests of each.

Taking account of two separate individuals' minds is more representative of the interpersonal exchanges that occur in care relationships than an extended theory. In my own life, as a severely disabled individual, I have utilized the help and assistance of caregivers. In the process, while my desires, goals, and well-being are of central importance, it seems inappropriate to perceive my caregivers as an extension of me. It is true, my own caregivers compensate for capacities I may lack, but I frequently negotiate with my caregiver(s) as a separate entity, to appropriately assess whether my requests are reasonable. Indeed, there is an operative assumption that I negotiate with another, separate agent, and this assumption plays an integral part of the interdependent nature of our relationship. Thus, a metaphor of extended mind might be useful in some contexts that include a cognitively disabled person and their caregiver. In other contexts, a

metaphor of extended mind threatens to presumptuously negate crucial aspects of the caregiver's and the cognitively disabled person's humanity and identity.

2.4. Conclusion

Taking account of the social world in which persons with cognitive disabilities exist is important, because it provides a theoretical structure that broadens our ability to perceive cognitively disabled persons as capable of giving or withdrawing consent. This opens up the possibility of acknowledging when a cognitively disabled individual's autonomy is neglected and disrespected. With this perception in place, we can begin to create guidelines, policies and laws that allow cognitively disabled persons to make decisions that are in their best interests to the best of their ability. Drawing from the literature on agency and cognitive disability, I discussed two issues that are relevant for accounting for the distinctive agency of the cognitively disabled: paternalism, and extended mind.

The literature on paternalism and cognitive disability is useful because it draws attention to the possibility that other persons who share an individual's space can restrict one's agency. Paternalism makes it morally permissible for one agent to restrict the decision-making powers of another because of an intellectual impairment. However, Wikler's account seems to overly press the permissibility of other persons to restrict the agency of the cognitively disabled person, and he downplays or ignores the person's capacity for autonomous agency. Therefore, it is necessary to develop an account for when one agent can help and improve the autonomy of another. At the same time, it is important to keep in mind that there is a possibility that under some conditions some persons may appropriately restrict the decision making powers of the cognitively disabled. In such cases, merely having a cognitive impairment is not enough to restrict liberties. The impairment has to affect one's capacity to make decisions. Moreover, if we consider the social

world that a cognitively disabled person occupies, the impairment must also affect one's ability to negotiate the social world in a way that impairs one's capacity to draw from the cognitive assistance that others give.¹¹

One promising theory that can account for the potential of agents to draw from the environment to improve one's autonomy is extended mind theory. If the mind extends into the environment, then we can use objects and other agents to carry out decision making and other cognitive tasks. Indeed, much of the literature on agency and cognitive disability draws from metaphors of extended minds. However, extended mind theories are controversial and marred with problems. It is questionable whether the mind is extended in exactly the same way that theorists presuppose, and it is even less plausible whether it can provide an adequate conceptual framework to account for the agency of persons with cognitive disabilities. With that being said, my own account will not be an extended mind theory. I do not claim that extended mind theories are false, but I propose a less presumptuous view. I propose that cognitively disabled individuals are "helped" by other agents. Persons *assist* cognitively disabled individuals by helping them make decisions, by taking over for cognitive capacities that are lacked by the individual, but are required to make decisions. This involves promoting or facilitating capacities that are intact in the disabled person. I draw a necessary distinction between persons and their caregivers, but point out that both parties still interact in interesting and novel ways.

Theories about shared agency -or theories about when two agents jointly participate to carry out an action- provide a promising and useful conceptual framework for developing an account of the social nature of agency and the autonomous agency of persons with cognitive

¹¹ Severe forms of autism are a candidate for a disorder that affects one's capacity to both make decisions and negotiate the social world.

disabilities. In the next chapter I present, develop, and critically discuss some contemporary accounts of shared agency. However, when accounting for the social existence and experiences of cognitively disabled persons, I argue that their agency is not entirely shared with caregivers. Rather, the social worlds in which persons with cognitive disabilities are embedded with their caregivers are worlds that are similar to cases of shared agency, but different in crucial respects that I will describe. So, there are limits to what is shared. To account for these differences, I introduce a unique form of agency where persons are assisted with making decisions and carrying out actions. I call this new form of agency, “helped agency.” Helped agency is the conceptual framework that I present for part of the social structure of cognitively disabled persons when they are being assisted by others to form and execute decision-making tasks. While I elucidate the conceptual framework of helped agency, I will liberally borrow from some useful ideas and concepts found in theories of shared agency. It is to this theory of agency within helping contexts that I now turn.

Chapter 3: Helped and Shared Agency

Philosophers of action have developed a keen interest in the distinction between individuals acting on their own and individuals acting collectively. Developing a conceptual framework for shared intention and activity is of interest for a variety of disciplines including political science, ethics, law, social science and psychology. The central question pursued by these theorists of action is to answer the question, “what is it to act together?” Indeed, this question has inspired answers that attempt to identify features, concepts and empirical implications of shared agency. It also has inspired answers that prompt further questions about how far shared and collective agency can be reduced to a study of individual agency. While there is little dispute that shared activity, joint action, and collective action exist, there is widespread disagreement about how exactly one understands these activities. Michael Bratman is a philosopher who has devoted considerable attention to shared agency and a large part of his philosophical career to exploring agency and intention within social contexts.

In this chapter I expand on the ideas that I developed in the previous chapter about how to account for the agency of persons with cognitive disabilities within their social environment. In previous chapters I argued that little attention has been given to the social environments of cognitively disabled persons, which often includes other persons that help formulate and carry out their intentions. The account offered by Francis and Silvers draws an analogy between a prosthetic device and the way a trustee assists a cognitively disabled person to make and carry out decisions. Other theories understand the trustee or proxy decision maker as a literal extension of the agent. These theories were vulnerable to criticism and failed to adequately acknowledge the trustee or caregiver as an agent with a mind, intentions, values and beliefs. Philosophical accounts of shared and joint action are one way we can understand how agents -including

cognitively disabled persons- are embedded in a social world. These accounts are originally presented by philosophers to flesh out the details about what occurs when we act in unison with another agent. In the social world we occupy, we frequently come together in philosophically interesting ways that I think are relevant to the cognitively disabled. I take it that one way we can act together is when another person helps us perform an action that we may not be able to do on our own. Disabled persons often live similar interdependent lives wherein a person assists them perform actions like opening doors, pulling out chairs, or pushing wheelchairs across unfamiliar terrain. In contexts featuring a cognitively disabled person, trustees can enter into a cognitively disabled person's social space, help the disabled individual formulate their own decisions, and help them carry out their decisions. This chapter will liberally borrow from the literature on shared agency to elucidate what goes on when a trustee or caregiver helps a cognitively disabled person decide and carry out actions. I do this with the intention of providing a conceptual framework for understanding a cognitively disabled person's agency within contexts when they are helped. I call the agency "helped agency" or "helping agency" (HA). The chapter concludes with speculation on the practical and moral implications of this conceptual framework.

3.1. We-Intentions and Helping-We-Intentions

One necessary element of shared agency can be understood within a context of answering perplexing ontological questions regarding two comparable cases. Consider a pair of cases discussed by John Searle, where a large number of individuals are in a park (Searle, 1990, p. 402). In the first case, the individuals are picnicking and it begins to rain. Each person runs to a gazebo in the center of the park for shelter. It is assumed that this example is not a case when individuals do something together, and they are not acting jointly together, even if they may be responding to each other in some regard. In contrast, consider a second case where the same

individuals execute the same bodily movements, but act as members of a dance team who are performing a piece in a park. In both cases there is an equal aggregation of individual behavior. The dancers appear to be engaged in a shared action, yet the picnickers do not. What distinguishes the two cases? Philosophers have answered this question in a variety of ways, and many of the answers incorporate ideas about intentional attitudes.

Searle suggests that what distinguishes the two cases is the creation of a so called “we-intention”. In other words, it is not the outward behavior to which one should be paying attention, nor to the aggregation of individual actions, but something about what the participants take themselves to be doing. What the participants take themselves to be doing can be loosely described as an “intention”. While in both cases each participant intends to run to shelter, the collective case involves an intention about what the others are doing, and this intention is expressed by the utterance “we are performing a dance where we are running to the shelter.” Michael Bratman describes this sort of action as “shared intentional activity”, and suggests that there are times when agents act together in a stronger sense than two agents merely responding to each other. Bratman describes shared intentional activity as follows:

[t]hey each see their own activity as embedded in what they are doing together, and this understanding of their individual activity as embedded in their shared activity is a central element both in their guidance of that activity and in their and our understanding of what they are doing. (Bratman, 2010, p. 8)

Likewise, intentions are integral to the content of HA. When a caregiver takes over for cognitive abilities that are lacked, the caregiver must do so with a “helping-we-intention”. A helping-we-intention is partially an intention to help or altruistically assist the cognitively disabled person, and compensate for whatever cognitive abilities may be lacked or required. The assistance given can be altruistic because in some cases the cognitively disabled person’s

intentions may be prioritized, and the trustee may act, to some degree, without regard to their own interests. This intention is also partially a modulation of a “we” intention, because the caregiver’s activity is embedded in what the caregiver and client are doing together. Although the primary goal and central focus would be on carrying out the cognitively disabled person’s wants, needs, desires and intentions, the caregiver is also acknowledged in the activity as a comparable agent. In this sense, a helping-we-intention, defers most decision making priorities to the cognitively disabled person.

By appealing to a helping-we-intention, part of an analysis can be given for when a caregiver wholly takes over the decisional capacity of a cognitively disabled person, rather than enabling that person. Consider a case when the caregiver paternalistically acts for a cognitively disabled person, without considering the cognitively disabled person’s wants, desires, intentions, or conception of the good. In this case, the “we” part of the intention is missing. While the helping part of the intention may still be present, the understanding that the activity is embedded in what the caregiver and the assisted are doing together remains absent. Therefore, the absence of a “we” intention contributes to an analysis of when a caregiver wholly decides for another person, rather than *helping* the cognitively disabled person make self-governing decisions.

The helping-we-intention marks a distinction between an action that is jointly shared, and an action that is helped. In other words, an action that is helped has an additional element of intending to assist the other party, and make up for whatever cognitive or physical capacity that may be lacked by a disabled person. In contrast, when an action is simply shared, both parties do not need to intend to make up for whatever cognitive or physical capacity is lacked. Therefore, the intentions differ between shared agency and helped agency.

When participating with others, when sharing an intention, and when acting with others, an individual must be in an appropriate relation to other agents. The intention one has

when acting with another must also be compatible with the other(s)'s. Consider an agent A who forms the intention to go to the mall with agent B, while B forms the intention of spending the day at the movie theater with A. A's and B's intentions are incompatible. Therefore, there would be no shared intention or shared action. Furthermore, suppose that A and B both intend the same thing, but disagree about how to go about acting. In this case, A and B have different and incompatible plans. Therefore, they will not rightly share an action. For a joint or shared action, it appears that there must be compatible intentions and plans between the two agents.

Similarly, in HA, when a trustee assists a disabled person, both parties must be in an appropriate relation to each other. Suppose that a caregiver has different and incompatible intentions than their disabled client. The disabled person forms the intention to go to a movie with the trustee, but the trustee forms the intention to go to the library with the disabled person. In this case both agents take themselves to be doing different things, and the caregiver cannot rightly be said to be helping the disabled person. Furthermore, the caregiver and their cognitively disabled client might formulate different and incompatible plans to accomplish a task; in this situation the cognitively disabled person is not rightly understood as assisted or helped.

One of the challenges of giving care is ensuring that the plans and intentions of both parties are compatible. Indeed, I acknowledge that much of the burden of compatibility is placed on the trustee for negotiating both party's intentions and plans in a way that does not frustrate the helped action with a disabled person. In my own life, as a physically disabled client who requires some assistant, I also have to negotiate the caregiver's intentions or plans and sometimes there is incompatibility. In these cases my caregiver will not be able to act together with me or help me. In some cases, I can imagine that some cognitively disabled persons may lack the necessary capacity to ensure that both party's intentions and plans are compatible, so the caregiver may need to compensate for this capacity. That being said, it is certainly not impossible for a caregiver

and a disabled person to have compatible intentions and plans, even if there may be some challenges to ensuring compatibility. In cases where compatibility of intentions and plans is maintained, the disabled person stands a good chance of being assisted.

3.2. Planning

A large part of Bratman's thesis on shared activity involves planning and coordination of said plans, which he understands as "a distinctive kind of goal-directed agency, one that involves attitudes of intention, many of which are future directed." (Bratman, 2010, p. 9) Consider an agent B who intends to attend a lecture the next day. The intention is accompanied by goal-oriented behavior, and further "sub-plans", for B to successfully carry out his intention and act. Agent B must plan a course of action to get to the lecture, ensure there are no other incompatible dates, double-check the location of the lecture the next day, and do so within a limited temporal framework. Similarly, in shared contexts, agents form intentions -including the necessary we intentions- and plans, all of which must be compatible with each other, if one is rightly understood as acting with another.

Furthermore, Bratman requires that a shared action has a "meshing of subplans". To elucidate his views on meshing subplans, Bratman presents the following example:

Suppose you and I each intend that we paint the house together. However, I intend that we paint it red all over, and you intend that we paint it blue all over. We each know this about the other, now that we each know this, and so on. And neither of us is willing to compromise. Even if as a result we end up painting the house together...ours would not be a [shared action]. (Bratman, 1999, p. 99)

Bratman's diagnosis of what goes wrong in the painting example is that there is some sort of disagreement about subplans. Each agent disagrees about which color the house is to be

painted, and hence each agent lacks a necessary element to acting jointly together. It is notable that simply having a difference in subplans does not imply that they fail to “mesh”. Suppose both agents plan to purchase paint at a different store, but agree about the color. None of the agents really care about where the paint is purchased, so the activity could still be cooperative and shared. The requirement, for Bratman, is that the subplans “mesh”, not that they are the same.

Planning and meshing of subplans would also be a necessary and important element for HA. When a caregiver helps a cognitively disabled client to form and carry out decisions, future-directed and goal-orientated intentions need to enter the conceptual framework. Furthermore, the caregiver may have to help the cognitively disabled client formulate the necessary plans to carry out the action, since this capacity may be lacked or impaired in the cognitively disabled person. Alzheimer’s disease is a relevant disorder where a person may have difficulty forming plans and future directed behavior, because the disorder deleteriously affects systems devoted to the function of working and prospective memory. As such, one may forget that they have already taken a pill, or they may forget that they performed the appropriate steps required to perform the action. Furthermore, an action may require further sub-plans, and the caregiver may need to help formulate and carry out these sub-plans. If the plans and sub-plans are incompatible between the caregiver and their cognitively disabled client, then this frustrates the success of the caregiver helping the cognitively disabled person to form and carry out an action, and the success or failure of the caregiver affects the autonomy of the client.

3.4. Shared Cooperative Action

There are actions that appear to be “shared,” in the sense that all the agents involved respond to each other, yet the agents also appear to act against each other. Consider a war wherein each side responds to the other with the intentional attitude expressed by “we are at war”

or “we are in combat.” Each side is mutually responsive, because each agent is responsive to the actions and perceived intentions of the other. At the same time, each side understands that the other party similarly responds, yet they do not cooperate with the other. For our purposes, it is important to draw a distinction between a shared action that is only mutually responsive to the other party and a shared cooperative action. The purpose of this chapter is to explore relevant concepts and ideas of agency relevant to HA, and it seems impossible to engage in helping another while being uncooperative. So this chapter will focus on what Bratman calls “shared cooperative action” (SCA) and the conditions relevant to SCA.

In an essay exploring SCA, Bratman outlines and elucidates three important elements of SCA: mutual responsiveness, commitment to the joint activity, and commitment to mutual support (Bratman, 1999, pp. 94-95). “Mutual responsiveness” denotes the aspect of SCA where each relevant agent is responsive to the other (Bratman, 1999, p. 94). Commitment to the joint activity refers to the idea of a commitment to the action and “the mutual responsiveness in the pursuit of the commitment.” (Bratman, 1999, p. 95) Finally, for an action to be an SCA, there is a commitment to mutual support, where each agent commits to supporting the efforts of the other to play their particular role in the shared activity (Bratman, 1999, p. 95). I think all three elements are important to HA, so I will develop them further, by borrowing from Bratman’s helpful analysis.

3.4.1. Mutual Responsiveness

There are two relevant concepts associated with the mutual responsiveness condition of SCA: a normative concept associated with responding to the other party; and an epistemic concept associated with what each party knows or understands about the other. The first concept refers to the idea that each party reacts to the actions and perceived intentions of the other. The

second concept is an epistemic condition where each agent *understands* that the other party is responding to their actions and perceived intentions. Indeed, when one is engaged with others and acting with them, one tends to respond as if the other has intentions, emotions, a will and a mind. Presumably one also makes predictions -albeit in a limited sense- about what the other intends, wills, thinks, and feels. Mutual responsiveness is a condition for SCA, and without it, neither party could cooperate with the other.

There is some evidence that caregivers and cognitively disabled persons corroborate the responsiveness conditions when a caregiver is providing assistance. Connie Kasari and colleagues compared the interactions between caregivers with autistic children and caregivers with other “developmentally matched mentally retarded and normal infants”, and report that caregivers respond differently to children’s specific impairments (Kasari, Sigman, Mundy, & Yirmiya, 1988). Confirming the responsiveness of the caregiver to the children, Kasari and colleagues state, “[c]aregivers are surely responding to characteristics of their children’s behaviors.” (Kasari, et al., 1988, p. 55) Sadly there is limited research on how a cognitively disabled person interacts with their caregiver. However, presumably if HA is a real possibility for a person with a cognitive disability, they would also need to be responsive to the caregiver’s efforts to support them the way that a physically disabled person is responsive to their caregiver. If the disabled person is not responsive to their caregiver in any way, then the disabled person’s autonomy will be supplanted by the caregiver and not enabled.

3.4.2. Commitment to the Joint Activity

What does it mean to have a commitment to the joint activity? Bratman suggests that this involves an “intention in favor of the joint activity.” (Bratman, 1999, p. 96) I take Bratman to be implying that both parties need to approve of the action, by officially or implicitly agreeing to the

action, or accepting that the action is satisfactory. What it means to have a commitment to the joint activity also integrates Bratman's ideas about plans. He argues, "our conceptions of intention also significantly involves our conception of the roles of future-directed intentions and partial plans." (Bratman, 1999, p. 97) Planning involves goal-directed behavior or attitudes that are incorporated into the action. To use an example presented by Bratman, one can figure out how to support a partner's singing in a duet in a myriad of ways: helping them find a note, provide tapes to listen to, and helping anticipate obstacles that may prevent one from showing up on time. Bratman says that the planning aspect of the intention "supports the legitimacy of the appeal to my intention that *we J.*" (Bratman, 1999, p. 98) If we take Bratman's proposal seriously, in order for agents to act within a context of SCA, they must cognize and carry out the appropriate steps (carry out a plan), with an understanding of the timing and resources to be used in order to achieve the objective.

In contexts that include a cognitively disabled person and trustee, there also must be a commitment to the joint activity. Both parties need to approve of the action, and find the action satisfactory. However, the approval of the action may not necessarily involve a *full* understanding by the client of what the action requires. Part of a challenge for a caregiver that works with a cognitively disabled client may be that the client does not fully understand what the activity requires. Consider a person with Down's syndrome, call him "Steve", who has a desire to go to the store and buy a particular model car. He expresses his desire to his caregiver, yet does not fully understand what is required to fully accomplish the desired goal of obtaining the car. The caregiver acknowledges Steve's desire and proceeds to form plans and sub-plans to fulfill Steve's desire. Steve may lack a certain epistemic understanding about how to fulfill his desire, but he can still approve of the plans that the caregiver has formulated, and he is committed to the joint action of getting the desired model car. If Steve did not approve or commit to the joint action and

generally disapproved of the caregiver plans, then Steve and the caregiver would no longer participate in a SCA or HA.

3.4.3. Commitment to Mutual Support

The commitment to mutual support is a commitment of both parties to support the other's attempts to play his or her role in the joint action (Bratman, 1999, p. 103). While commitment to mutual support may be a commitment necessary for SCA, it is not necessary for a shared action. Consider an example presented by Bratman of the unhelpful singers. Stewart and Juliette are singing a duet, and Stewart fully expects Juliette to get her notes right, but Stewart has no disposition to help her if she stumbled on her notes. If Juliette would begin to falter, Stewart would happily allow her to be embarrassed in front of everybody. Similarly, Juliette intends to sing her notes in a way that meshes with Stewart. But if he stumbles, she would not help. Each singer intends to mesh their subplans and sing the duet together, yet they do not have support necessary for SCA. Bratman says, “[i]f we, as unhelpful singers, do in fact sing the duet together our singing may be jointly intentional; but it is not SCA.” (Bratman, 1999, p. 104) The case of the unhelpful singer shows that one may have the intention that we J, but that does not ensure that one cooperates with the other. Furthermore, the requirement of mutual support for SCA implies that both parties are willing to retain the joint action in the face of adversity and barriers when jointly acting.

There is a degree to which one is willing to help another, and the degree one is willing to provide support is relative to one's physical and mental capacity. If one cannot lend support to the other, because of their physical and mental limitations, then one may not be expected to support the other in every aspect. But what conditions must be satisfied to offer mutual support for SCA? Firstly, one must satisfy the first two conditions for SCA: one must be responsive to the

other; and both parties must jointly commit to the action. Secondly, one party may require help from the other to act in a way that is necessary for their action to be successful. Thirdly, the other party must be able to help without undermining their own contribution to the action. Fourthly, there is no coercion for the other party to help the other in their role of the activity. Fifthly, all of the above is commonly known or understood. The five conditions are all relevant to circumstances when one party would offer the other party necessary help to carry out the action.

Is the commitment to mutual support a necessary element to HA in contexts that include a caregiver and cognitively disabled person? I think so, to some degree. Recall that in HA a caregiver takes over for whatever cognitive capacities may be lacked or restricted. While it is obvious that the caregiver is committed to helping the cognitively disabled person carry out an action, it may be less obvious that the cognitively disabled person is committed to supporting the caregiver. However, for HA, the cognitively disabled person must contribute in some way to the action, otherwise the caregiver is not enabling the disabled person to act. Instead they would be supplanting the action. In other words, without the cognitively disabled person's contribution to the act, there is no basis on which to say that the caregiver "helps" or "enables" the person make self-governing decisions. The cognitively disabled person may contribute to whatever degree he is able, and is required to do so. Otherwise he is not really making decisions for himself. Furthermore, if the cognitively disabled person attempts to make a contribution to the action, yet the contribution is denied or thwarted by the caregiver, then the cognitively disabled person is no longer being helped in the appropriate way for HA. So, the idea of having the cognitively disabled person contribute to the joint action, and having their contributions acknowledged is an aspect that is inherent to the content of HA. However, the idea of "mutual support" may be called into question by cases involving persons with *severe* cognitive disabilities and the caregivers who help them. In fact, a plausible argument could be made that a greater severity of the cognitive

impairment may push the assessment of the action from the helped autonomous end of the agency continuum to the paternalistic end

The idea of “mutual support” can imply that the two parties providing support are equal with respect to certain capacities and intellectual powers, and it may also imply that each party can contribute in relatively the same way. It was this sort of mutuality that inspired John Rawls to embrace the image that all parties in a social contract must be roughly equal with respect to physical and mental abilities (Rawls, 1971). Rawls’s commitment is controversial because in cases where there is a large asymmetry of power between parties, it is no longer mutually advantageous for both parties to be included in a social contract. Martha Nussbaum argues, “Rawls would ultimately need to jettison the idea of rough equality in power and the related idea of mutual advantage as the aim of the social contract, were he to be able to do full justice to the claims of people with disabilities.” (Nussbaum, 2009, p. 334) According to Nussbaum, Rawls’s theory of justice fails to adequately provide justice for persons with disabilities and cognitive disabilities in particular, because of the deep commitment to the ideas of similarity of power, mutual advantage, and rationality of all the parties involved in a social contract. Therefore, Rawls’s social contract theory cannot address cognitive and physical disability without a major overhaul that would appropriately recognize the distinctive needs and interests of people with disability. In place of Rawls’s social contract theory, Nussbaum offers an alternative approach to justice that begins with the problem of how to provide justice for those who are at a social disadvantage and differing abilities (Nussbaum, 2009, p. 334). Nussbaum outlines her approach in *Frontiers of Justice* and labels her new approach to justice the “capabilities approach”. (Nussbaum, 2006) (Nussbaum, 2009)

Does cognitive disability create a similar problem for the commitment to mutual support in Bratman’s analysis of SCA? Something like mutual support might be useful for analyzing HA,

because in cases of HA a person with a cognitive disability must contribute in some way to the joint action. Otherwise they are being supplanted and not being helped or enabled. However, there is a sense in which the mutual support condition can be too strong, because the assumption of mutuality may rest on an idea that persons contribute to an action with the same degree of support and with roughly similar capacities. Call this reading of mutual support “the strong reading.” There is a weaker reading of mutual support that simply implies that each party is committed to supporting the other party, in whatever way they can. In the weaker reading of mutual support, each party is not out to thwart the other’s attempts if they happen to falter, but supports them, if they can. The weaker reading can be adjusted to fit two persons committed to the joint action, no matter how disparate their abilities or modes of performance. However, there could be contexts where a person may not be able to contribute anything to the other party, except to express their desires, intentions, verbal guidance and goals. Consider a severely disabled person called “Christopher” who cannot move, but can fully communicate. Christopher expresses to his caregiver that he wishes to have a bath, and expresses this desire with the utterance, “I wish to have a bath, let’s go to the bathroom and bathe me.” The caregiver forms the intention to comply with Christopher. There is a sense in which Christopher cannot provide mutual support to the action of having a bath, and the caregiver is the primary person to carry out the action. However, even in this case, Christopher can still contribute to the action, because he can still communicate. If he has feeling he can say when the water is too hot, he can tell the caregiver that he is uncomfortable, he can tell the caregiver if he has soap in his eyes, and the caregiver relies on Christopher to inform her as such. In this case, according to the strong reading of mutuality, there is very little mutuality in the support being offered. On a weaker reading, both parties are contributing in the way that is expected of them given their different modes of

performance. The weaker reading of mutual support is the more attractive reading for HA, because HA often includes radical disparities in the support that can be offered.

3.5. The Practical and Moral Implications of Helped Agency

In this chapter, I presented a conceptual foundation for the agency of many cognitively disabled persons when it involves another person. The conceptual foundation has borrowed from ideas found in the works of philosophical theorists who analyze joint action and shared agency. Necessary to the analysis of HA are the following concepts: helping-we-intentions, plans, subplans, commitment to the joint action, mutual responsiveness, and mutual support. I elucidated how each element can be useful when providing an analysis for when cognitively disabled persons are being helped by another agent, and I made some minor adjustments to the concepts when needed. The motivation behind HA was to account for the dynamic interactions that are involved when cognitively disabled persons make decisions within a social context of being helped or enabled. This conceptual framework is a more satisfying alternative than other theories being offered, because it acknowledges the agency and capacities of all parties involved. It does not understand caregivers as an extension of the cognitively disabled person or a cognitive prosthesis, but it incorporates the trustee or caregiver into the actions of the disabled person as another agent with a different will, mind, beliefs and intentions. In this sense, the agency of a cognitively disabled person who requires the assistance of others is more like a shared agency or joint agency, rather than an agency that extends out into the world.

What is the difference between shared agency and helped agency? One distinction between helped agency and shared agency is with the different intentions that each party has when participating in the activity. In helped agency, the helper forms an intention that has two features: a we intention and an intention to help the other party. This allows one to distinguish a

shared activity and a helped activity. A helped activity enables the other, while a shared activity does not incorporate intentions to “help” or enable the other party. Going on a date is an example of a shared activity that is not necessarily a helped activity. There is no clear way one could assert that going on a date enables another. Another difference between a shared agency and helped agency is that a helped action often incorporates a weaker mutual support condition than most shared actions, because of the radical disparities that are encountered when one provides help to another. However, many of the conditions associated with a shared action are also present when one enables another. The theory of HA shares many of the conditions that theorists have presented for shared agency. This suggests that HA is within the same family as shared agency and shared agency is a family resemblance concept that has HA within its “family”. Members of the family resemble each other though features that are shared by some, but not all members of the same group that we associate with a shared activity. Understanding shared agency as a family resemblance concept is a good way to validate the ontological status of helped actions as also a type of shared activity. Thus, helped actions are shared, but they also have different features from other shared activities.

A practical implication that immediately follows from HA is that the person being helped can contribute to the action in some ways, and there is space to acknowledge how they can contribute to the action. Recall that one problem with some threshold views is that agency is primarily understood as individuals exercising their own capacities. Once a person falls below a threshold of individual capacity, the person can no longer make decisions for themselves, and the individual’s agency can be supplanted by another proxy decision maker on paternalistic grounds. If we perceive a person with a cognitive disability as capable of being helped in a context of HA, there is still room to acknowledge a person who falls below the threshold of individual capacity as an agent who can contribute to self-governing decisions in some way. Thus, HA allows for

persons with cognitive disabilities who fall just below a threshold to be perceived as full and self-governing agents.

HA accounts for a trustee's role in carrying out and forming intentions in a way that does not negate or downplay their agency. Recall that one issue with extended agency theories was that they inaccurately reflected the interpersonal dynamics of an actual care relationship. In my own care, it often involves negotiating with another agent and all of the complexities that accompany negotiating with that agent. Other conceptual frameworks for understanding the dynamics of a care relationship fall short of acknowledging these complexities, because they understand the trustee as closely akin to a prosthetic or external object. The latter conceptual framework runs the risk of ignoring what can actually go on in a care relationship.

By understanding the care relationship as a joint action, there are implications for pressing bioethical questions pertaining to giving care. Consider controversial cases of sexual facilitation. Sarah Earle describes sexual facilitation as follows:

“facilitated sex”...might mean that assistance is required to attend social events such as parties, or go to pubs and clubs...or that assistance is required to negotiate the price when using the services of a prostitute. More specifically, a person might be required to facilitate sexual intercourse between two or more individuals, to undress them for such a purpose, or to masturbate them when no other form of sexual relief is available. (Earle, 1999, p. 312)

In the above description, Earle describes a continuum of activities that might enable a person with a disability to be sexual via the utilization of a caregiver or nurse. Operating under the view that the caregiver is an extension of the person they care for, one can easily understand all the activities described by Earle as morally permissible, with very little cause for concern. After all, if the caregiver is understood as a prosthetic extension of the disabled client and the

client would otherwise engage in self-pleasure, then it seems as if there would be a very small logical step to concluding that the caregiver should provide masturbatory relief to the client as an extension of their care duties. However, if the care relationship is understood as a joint action and the caregiver is understood as another agent, then there is a real moral concern as to whether the caregiver consents to providing sexual relief. Furthermore, a worry arises that an understanding of the caregiver as an extension of their disabled client or a cognitive prosthesis can encourage treating the caregiver as only a means to an end and merely instrumental to the disabled person's needs. If one acknowledges the caregiver as an agent, with the conceptual framework of HA, and the caregiver has not consented or is treated strictly as instrumental, then the conceptual framework of HA allows for there to be a reason for ethical concern.

Understanding the care relationship as a joint action allows one to draw distinctions between care that is provided by a human agent and care that is provided by a non-human. In a recent research report it was revealed that humanoid robots can potentially be utilized to train children with autism spectrum disorder to respond to social cues (Bekele et al., 2013). More specifically, children with autism have difficulty mastering the capacity for joint attention, and the robot teaches children with autism to coordinate their attention with other people and objects in their environment. One can imagine in the future that robotic technologies will play some role in human care, and perhaps even assist persons with disabilities in fulfilling a variety of life tasks similar to a nurse or caregiver. Understanding care relationships that involve other humans as a joint action allows one to distinguish between care that provided by humans for humans, and very similar care provided by non-agent technologies. While all care provided for humans may not be a joint and shared activity, when it involves another human agent, it is important to acknowledge the human dynamics that are involved. The dynamics involved in HA, I believe, closely constitute a care relationship for persons with disabilities and their caregivers.

Understanding care relationships in terms of HA, allows one to acknowledge some of the important dynamics and intentions involved when acting with another person. Indeed, as demonstrated, understanding care relationships as HA even has some theoretical advantages. However, there are some pressing issues involved with understanding a care relationship as a joint action. More specifically, problematic cases arise when persons have difficulty acting with other agents because of an underlying impairment. Additionally, trustees can take themselves to be enabling a disabled person, when in fact they are supplanting the disabled person's agency, which can further complicate helping a cognitively disabled person. The next chapter will explore some complexities and possible objections to understanding a care relationship in terms of HA. However, I do so with the following proviso: even if one were to acknowledge the complexities and theoretical problems involved when understanding a care relationship as HA, HA is still a better and more complete representation of care relationships than other conceptual frameworks offered elsewhere in the literature on cognitive disability.

Chapter 4: Complications and Possible Objections to Helped Agency

In the previous chapter I argued that care relationships should be understood as a shared cooperative action. Within my analysis of helped actions, I liberally borrowed from useful concepts related to shared agency which included the appropriate intentions, plans, mutual responsiveness, commitment to the joint activity and commitment to mutual support. These concepts proved useful when analyzing how one person enables another with limited cognitive capacities. The conceptual framework of shared agency provides promising conceptual resources for analyzing the dynamics of how trustees can aid cognitively disabled persons and enable them in exercising their agency and autonomy. If one understands care relationships as a joint action and as a helped agency (HA), then there are a number of objections that can be raised and complications to consider. This chapter will present, explain, address, and respond to them.

The first objection addresses whether a care relationship and actions related to care are best understood within the framework of HA. This objection relies on the premise that care relationships do not resemble HA, and one should not falsely construe care relationships as a joint activity. I argue that this objection fails. The second objection to consider is related to when a care relationship includes a person with autism whose capacity to cooperate with others is compromised. I argue that while this sort of impairment is notable and creates a complication for the HA theorist, the existence of autistic individuals does not imply that my thesis is incorrect. In fact, I argue that one of the challenges of working with autistic persons is that the impairment can frustrate attempts to cooperate with them in a care environment. The third objection or complication to HA, is based on cases when caregivers ascribe agency related capacities to the disabled person, when the person does not have the capacities that are ascribed to them. One case when caregivers unjustifiably ascribe agency related capacities is when a trustee attempts to

facilitate communication for a severely autistic individual. I argue that such cases do not imply that my thesis is false. Furthermore, future research can elucidate when caregivers misperceive when decision making capacities are present and when they are not.

4.1. Is Shared Decision Making The Right Model?

The first objection against HA is based on whether shared agency, joint activity, or collective action is the correct framework for understanding the agency of cognitively disabled persons in care relationships. I wish to consider two types of cases when HA may not be the best conceptual framework to use. The first kind of case is when the trustee disagrees with the cognitively disabled person's decision on the basis of what would be in that person's best interest. The second kind of case involves examples of when an individual with a cognitive disability has such a severe impairment to their decision-making faculties that it is impossible for them to have any meaningful contribution to the helped action.

Consider a case when a cognitively disabled person named Aaron wishes to do something that may not be in his own best interest or well being. Suppose the potentially damaging desire is a desire to consume Halloween candy for breakfast and lunch. Aaron requires his caregiver, Jane, to carry out this action, because she has the necessary cognitive tools to plan the course of action to get Aaron the candy. Jane thinks that this tactless consumption of candy would not be in the best interest of Aaron, because she fears an uncomfortable tummy ache would be in his future if she wantonly assisted him. One might argue that we have a clash of views in this case, and therefore HA is not the best framework to understand care relationships. However, I think that HA can still be useful for analyzing the situation. Recall that HA understands decisions with regard for all agents' wants, desires, and beliefs. While I acknowledge that in most cases one ought to prioritize what the cognitively disabled person desires over what the caregiver thinks

ought to be done, I also acknowledge that there may be exceptions. In cases where views might clash, there is still room to prioritize what the caregiver thinks is best. The idea of incorporating both agents is to at least *consider* Aaron's tastes and desires. Jane can do so, but still override Aaron's tastes or desires that lead to potentially damaging results. Granted, in this case the conceptual model is close to a paternalistic model of decision making, but the effort that is put forth is HA. In other words, ideally, the intention is to act together with Aaron and consider his wants, feelings and desires, but there are exceptions to the rule. Furthermore, in cases where the intention is to act together and enable Aaron, compromises usually occur. For example, when negotiating a compromise, Jane might communicate to Aaron that she understands what he wants, but points out the potential risks. She then recommends another course of action that incorporates Aaron's love of candy, but recommends a less harmful alternative. In cases of conflicting beliefs, shared decision making can still occur; thus, conflicting beliefs do not pose a serious threat to the HA theorist.

The second type of case involves an individual with an extremely severe impairment that results in most of their decision-making faculties being compromised. Consider a case where agent A is not only below a threshold of being able to make decisions for themselves, but is below a threshold to such a degree that they are barely cognitive at all. Persons with an extremely progressed Alzheimer's disease or minimally conscious states are a good candidate of such a condition. In this case, the person still requires care, but cannot contribute anything to an action. The conceptual framework of HA would not be adequate, because they fail to meet most of the conditions for HA. In this case, it seems that another model of care is more appropriate. I concede that this sort of case would add a complication for HA theorists to consider, but it does not imply that this model is false. In cases where a caregiver enables a person when their cognitive faculties are limited, HA works quite well. However, in cases where the cognitively impaired person

cannot contribute to the action in any meaningful way, a more paternalistic model might be more appropriate.

There are limitations to how paternalistic a caregiver can be. Ideally, incorporating an agent into the decision making process should be a primary goal. In cases of advanced stages of Alzheimer's, there is still an opportunity to incorporate the impaired person to at least some degree, if one considers and prioritizes who the person was in the past and what their values were. The idea behind this suggestion is to incorporate who the person was prior to the condition that compromised their judgment. This sort of decision making process would involve the memory and imagination of the proxy decision maker. The decision maker would need to remember who the agent was in the past and imagine how the person would act if the person were entirely cognitively engaged. However, there are additional complications to this proposal, since there are a number of factors that could compromise the ability of the proxy decision maker to accurately remember. Furthermore, it is questionable that in all cases of exercising one's imagination he or she can accurately predict what the cognitively disabled would want. With these limitations in mind, I still think that there are ways of incorporating the other into an action, even if one's decision making faculties have been mostly compromised. Cases of advanced neurodegenerative diseases are at least one potential candidate for when a proxy decision maker would incorporate the person into the decision in this way by remembering and imagining.

Not all cases of cognitive impairments can easily incorporate a cognitively disabled person into the decision by remembering who the person was and imagining how they might act. In cases involving severe forms of neurodevelopmental diseases, proxy decision makers can have virtually no opportunity to observe or consider how the person was prior to the condition. As such, one's imagination and memory would be less reliable for incorporating the cognitively disabled person into the decision making process. In this case, a stronger paternalistic model may

be in order, because the proxy decision maker will not be able to draw on past experience and exchanges with the cognitively disabled person. Therefore, in these types of cases, the proxy decision-maker can only rely on their best judgment regarding the well-being of the person that they are deciding for. Therefore, imagining what the person with certain neurodevelopmental disorders might be like without their impairment is a limited, if not hopeless, endeavor.

The point I wish to make clear is that HA is a thesis that incorporates the cognitively disabled person into the decision making process, if they have some decision making power or they have some ability to be enabled by another person. There are many cases when the cognitively disabled individual may completely lack any related cognitive capacity to make decisions, and lack any related capacity to engage in enabled decision-making with a trustee. In these cases, HA would not be an option for them, and a paternalistic model would be justified. However, even with these limitations acknowledged, for many cognitively disabled individuals, HA is still the best framework for understanding how they can be assisted or enabled.

4.2. The Case of Autism and other Social Disorders

Other cases to be considered by the HA theorist involve disorders that affect a person's social agency and limit their capacity to communicate or cooperate. These disorders pose a problem for HA theorists, because HA construes care relationships as a cooperative shared action. If the nature of one's impairment prevents one from cooperating with a trustee, then one's impairment also hinders the capacity to participate in a shared or cooperative action. If one's impairment hinders the capacity to participate in a shared or cooperative action, then it can also critically hinder a trustee's attempt to enable the cognitively disabled person. If a caregiver's attempts to enable a cognitively disabled person are critically hindered, then HA is not the best model for care relationships that involve disorders affecting one's capacity to communicate and

cooperate. Thus, HA is not the best model for care relationships that involve persons with disorders affecting this capacity. Moreover, one might be tempted to conclude that HA is probably not the best conceptual framework to understand care relationships that involve persons with cognitive disabilities in general. This argument is particularly problematic for those affected by autism, a type of disorder that can hinder one's capacity to cooperate or communicate in social relationships. I will describe this condition and how this impairment may frustrate efforts to enable cognitively disabled individuals to make this objection more salient.

Autism spectrum disorders are a group of disorders along a continuum of severity that are associated with deficits of social skills, communication, and "restricted repetitive and stereotyped patterns of behavior, activities, and interests." (Tuchman, 2003) Although there is some debate about whether autism is best understood as a distinct impairment or a group of disorders along a continuum of severity, the recent consensus is that autism is a group of disorders with varying degrees of severity (Tuchman, 2003; Valente, 2004; Vokmar, Lord, Baily, Schultz, & Klin, 2004). Since autism exists on a spectrum, with varying degrees of severity, it is best understood on a case-by-case basis, while acknowledging the immense variation between persons with the condition. Persons with autism can display varying degrees of capacity with regards to social skills, communication, or deviations of behavior. This can have implications for whether HA is a possibility for persons with autism, because not every person with autism will be incapable of acting and cooperating with a trustee. Furthermore, some high-functioning autistics can independently act without any trustees or caregivers at all. With this continuum and spectrum in mind, I will focus my investigation on the more severe cases of autism, wherein the autistic individual requires a caregiver. Presumably it is the more severe cases of autism that present the deepest problem for HA.

Impairments associated with social interaction are a common occurrence amongst persons with autistic spectrum disorders (ASD). The physical manifestations related to this social dysfunction can be observed at an early age at the behavioral level. Roberto Tuchman lists a number of behaviors related to social dysfunction in autistic individuals, including the following:

gaze avoidance, failure to respond when called, failure to participate within groups, lack of awareness of others, indifferent to affection or inappropriate affection, and a lack of social or emotional empathy. (Tuchman, 2003)

As autistic individuals become older, socially problematic behaviors can make it difficult for them to form meaningful friendships or negotiate romantic relationships (Stokes, Newton, & Kaur, 2007). A recent study investigated helping and cooperation in children with autism and concluded that autistic children may have difficulty cooperating in joint actions (Liebal, Columbi, Rogers, Warneken, & Tomasello, 2007). The study comparatively investigated children with autism and children with developmental delay and investigated how both groups performed cooperative tasks successfully. Although both groups cooperated with adults, fewer children with autism performed cooperative tasks successfully. Furthermore, once an adult stopped interacting, children with autism displayed fewer attempts to “re-engage”. The researchers suggest that the children with autism may not have formed a shared goal or shared intention with the adult, which suggests that persons with autism may have difficulty in performing shared activities (Liebal, et al., 2007, p. 234). The implication from this research for HA is that persons with autism may have a dysfunction that specifically relates to the possibility of being enabled by participating in helped actions. If HA is true, then care relationships are best understood within the family of shared cooperative activity. Yet, autistic persons may have dysfunctions specifically related to their capacity to cooperate and participate in shared activities (Jahr, Eldevik, & Eikeseth, 2000). Therefore, when shared cooperative activities are hindered in cases involving severe forms of

autism, one can object to the HA theorist that they are both incorrectly informed and wrong about care relationships. I will argue that one can still affirmatively hold HA, be correctly informed, and be right about care relationships, even in contexts that involve severe forms of autism. A deeper exposition of my response to this potential objection will be presented later.

Some autistic individuals have difficulty communicating. An inhibition to verbal and nonverbal abilities affects one's capacity to share information with another. On the speech side of language, some autistic individuals fail to develop expressive and receptive language skills, while other individuals' capacity to utilize language is "immature." (Tuchman, 2003, p. 916) Tuchman characterizes immature language as "echolalia, pronoun reversals, unintelligible jargon and abnormal melody (sing song prosody, monotonous tone, or abnormal tone)." (Tuchman, 2003, p. 916) Furthermore, persons with autism who have an adequate capacity to speak intelligibly still struggle with initiating or sustaining conversations. At the same time, autistics with the capacity for speech have limited skills with taking turns, understanding jokes, or interpreting sarcasm (Tuchman, 2003). On the interpretive side of language, autistic individuals can have trouble reading facial expressions, interpreting body language, and understanding intonation (Tuchman, 2003). On the more severe side of the autism spectrum, some autistic individuals remain nonverbal throughout the entirety of their lives. Deficits in language and communication skills are commonly -but not necessarily- observed in persons along the autism spectrum.

The impairments of language and communication that are observed in persons with autism have implications for HA. If someone cannot adequately communicate with others, express their desire, visibly communicate that they require assistance or communicate that they are interested in being helped, then it is difficult to see how that same individual can meaningfully contribute to a shared and cooperative activity with others. Therefore, some of the

more severe linguistic deficits observed in individuals with autism may cause a philosophical problem for the HA theorist.

Another behavior observed in Autistic individuals that is related to social dysfunction and communication difficulties includes a limited ability to empathize or identify with the subjective orientation of another person. In a recent study by R. Peter Hobson and colleagues, it was observed that autistic individuals scored lower on four tasks that are presumably related to one's capacity to empathize: emotional engagement, sharing experiences in joint attention, communication of style and shifting in communicative role (Hobson, Lee, & Hobson, 2007). Emotional engagement is the ability for persons to perceive and express emotion, and their reaction to the attitudes of other persons. Joint attention denotes the interpersonally coordinated relations with reference to objects and events in the environment. Communication style denotes an individual's penchant to adopt and integrate the expressive style of another. Communicative role shifting refers to the propensity of a person to adopt the role of another (i.e. adopt the role of teacher in relation to a learner or speaker instead of listener). If one has an impairment that relates to one's capacity to empathize and identify with the subjectivity of another, then it will presumably frustrate one's capacity to mutually engage with another in a way that contributes to a shared action or a helped action. More specifically, this capacity to empathize directly relates to HA's condition of mutual responsiveness and the condition of committing to joint action.

4.2.1. Replying to the Case of Autism

Cases when an autism-related impairment implies that one has difficulty functioning in helped actions are a problematic reality for HA. The impairments that one encounters when providing care for an autistic individual seem to be in tension with some of the elements required for helping an individual with a cognitive disability. My reply to cases of autism is not going to

be a traditional philosophical reply that would deny the existence and care challenges of autistic individuals. Rather, I acknowledge that to some degree, autistic individuals may have difficulty functioning in the helped actions that are implied by HA. However, further clarification of the nature of autism and HA will take the sting out of the objection. Therefore, autism may prove less problematic for theorists of HA than originally imagined.

Persons with autism and other disorders that affect one's capacity to engage with others are a distinct and unique care challenge for both the care provider and the person receiving care. It is reported that for physicians who encounter patients with ASD, the combination of difficulties with social interaction and communication creates a barrier to diagnosis and medical treatment (Venkat, Jauch, Russell, Crist, & Farrell, 2012). Many care givers of autistic individuals are parents who are also reported to have a unique challenge to providing care. In "How I Learned to DeStress", Lynn Glucoft, a mother of an autistic child, describes the challenges and stresses she faces as a parent who provides care. Expressing the emotional toll that it takes on her, Glucoft writes, "When I listen to friends and family talk about things that bother them. I barely have the patience to listen because they seem so trivial compared to the struggles I deal with." (Glucoft, 2006, p. 36) Another study on the quality of life for parents with high-functioning autistic children indicates that parents experienced lower quality of life with respect to variables like parenting stress, coping, and satisfaction with resources available to them. This does not imply that parents are victims of their children's impairments, but that they face unique challenges to caring for and parenting their autistic children that may need to be ameliorated (Lee et al., 2009). For example, it is suggested by the researchers that demographic and psychosocial variables accounted for most of the quality of life differences that are observed. Access to support associated with income may buffer some of the emotional stressors (Lee, et al.,

2009, p. 236). The research suggests that there are unique challenges to caring for autistic individuals.

Some of the challenges that are encountered when caring for autistic individuals can be understood within the framework of HA. This provides a good conceptual framework for understanding the unique challenges associated with caring for autistic individuals. HA approximates a care relationship when a caregiver enables a person with a cognitive disability or compensates for certain cognitive capacities related to decision-making. HA, and some of the conceptual conditions associated with it, should not be understood as necessary and sufficient conditions that are logically required for a care relationship. Rather, HA is a *prototypical* care relationship. The conditions provided in the previous chapter are at the core of what counts as an enabling relationship, and HA provides a loose standard for when a person is assisted by another. There can be instances when a condition is not met to some degree. In such cases, a care relationship may deviate from the standard, and enabling a cognitively disabled person may become more difficult. I will call this theory the “prototype theory of HA.” The prototype theory of HA can be contrasted with a “necessary and sufficient theory of HA.” According to the necessary and sufficient theory of HA, the conditions of HA are logically necessary and sufficient conditions for analyzing helped actions. If one condition is lacking for an action P, then the standards are not met for HA, and P is not, in any way, a helped action or shared action. In other words, if the conditions are not met, P immediately fails to be a helped action. According to this theory, a helped action is an all-or-nothing affair. The prototype theory allows there to be fuzzy conceptual space for when conditions are not met. We might still have a helped action, even if a condition for HA is not specifically met. When a condition is not met, the prototype theory can illuminate the specific challenges that accompany helping and enabling persons whose impairments imply that they have difficulty meeting conditions for HA. Moreover, if the

prototype theory is true, one can observe that when a condition is not met for HA, we might have difficulty classifying an action as helped or paternalistically made. The action may sit somewhere in the middle. This phenomenon is best explained by a prototype theory, because sometimes when a condition is not met, one might still be tempted to conclude that an action was, in some way, helped, but still does not fit as comfortably into the schema of HA.

With the prototype theory confirmed, I suspect that HA can still provide an adequate conceptual structure to understand care relationships for autistic individuals. Autistic individuals may still have some capacity to participate in HA, and that can be enough to engage in a helped action. Furthermore, when an autistic impairment specifically affects one's capacity to act within a shared action, the prototype theory allows there to be a "fuzzy sense" in which an autistic individual can be enabled within a helped action. The caregiver may struggle to act with the autistic individual and the autistic individual may struggle to act with the caregiver, because care relationships prototypically resemble HA. When the conditions are not met, this can result in challenges to the care relationship functioning in an optimal way. In fact, it would appear that understanding a care relationship as HA actually allows us to understand the experiences that are encountered by the care provider when giving care for autistic individuals.

4.3. The Objection Based on the Fallibility of the Trustee

The final possible objection that can be presented against the HA theorist is associated with a cognitive weakness of inaccurately detecting the agency of others in groups consisting of two or more people. When two people attempt to act together, individual people may fail to record or recognize the authorship of individual actions. This creates a problem for HA, because presumably to enable a disabled person in a situation that consists of a trustee and the disabled individual, the trustee needs to accurately attribute authorship and capacities to the disabled

person. Recall that if HA is true, ideally one should prioritize the needs, wants, and desires of the disabled individual in order to actually enable them. It should not be the case that the trustee attributes capacities, desires, or needs that are not there. Indeed, a potential danger for enabling a person with a cognitive disability is when a trustee falsely attributes beliefs and desires to the disabled individual, and mistakenly thinks they are enabling the other when they are not. This worry becomes more pressing if the phenomenon is a regular occurrence within the practice of giving cares or if it is an inherent cognitive weakness that occurs when we cooperate in group activities. If it is an inherent cognitive weakness, and we unreliably ascribe agency to others, then one cannot reliably say that persons with cognitive disabilities are being enabled in helped actions. We cannot reliably say that persons with cognitive disabilities are being enabled in helped actions, because asserting that a person with a cognitive disability is enabled when engaging in a helped action is itself an ascription of agency to others. But, this ascription is already assumed to be inherently unreliable; so, HA is false or needs revision.

Are there actual cases when agency or capacities are wrongly ascribed to cognitively disabled persons by trustees? One historically relevant example of this phenomenon can be observed when facilitated communication was utilized for children with autism or other communication disorders. In “The Social Functions of Consciousness”, Chris Frith describes facilitated communication and research that was done to prove its ineffectiveness. Facilitated communication was thought to be useful for helping children with communication impairments express their thoughts. To facilitate communication, a keyboard was placed in front of the children. Since the children could not use the keyboard alone, a helper placed the hand over the child’s to detect attempted presses and convert attempted presses into actual presses. Frith persuasively argues that under controlled experiments, “it was not the child who was communicating, but the facilitator.” (Frith, 2008, p. 234) Much to the dismay of parents and

facilitators, the expressed thoughts of the autistic child were projections of the person that was supposed to be helping them. Frith notes that when in a group that is acting collectively, one can become confused as to whether we or some other agent is behind the action. In groups of two or more people, it can become confusing about which person authored the action, and such confusion can result in fallibly ascribing agency or capacities to others that are simply not there.

The utilization of facilitated communication has a deep and dark history. In “An experiential account of facilitated communication” Jeff Sigafoos and Ralf Schlosser tell the troubling narrative of when facilitated communication can go horribly wrong (Sigafoos & Schlosser, 2012). During the early 1990’s the reliability of facilitated communication had been cast into serious doubt when experimental data showed that in many cases it is the facilitator who is communicating. In spite of this, Janyce Boynton started facilitated communication with Betsy, an adolescent with autism and limited language development (Sigafoos & Schlosser, 2012). Boynton assumed she was making real progress with Betsy, which inevitably led her to accept that Betsy was trying to communicate that she was being abused. Betsy’s family was torn apart, but later was exonerated when tests had proven that Boynton was the source of the allegations. In a related confession by Boynton, she describes how facilitators are indoctrinated into the belief that facilitation works and the belief that it is a reliable way autistic individuals can be enabled. Boynton describes the persistence of the belief system as follows:

Some practicing facilitators are deeply devoted to their belief system. They will do anything to convince themselves that what happened to me cannot happen to them. But, I say, it can, given the right set of circumstances, hubris on the facilitator’s part, a strong belief in FC [facilitated communication], and an unwillingness to look at one’s own behavior. (Boynton, 2012, p. 4)

While a large body of evidence suggests that the facilitator is communicating and not the person they are supposed to help, Sigafos and Schlosser report that facilitated communication is “having a revival”, and they warn that more tragedies can potentially follow (Sigafos & Schlosser, 2012). Facilitated communication highlights the tendency of well-intentioned enablers to wrongly ascribe agency related capacities to the people they are attempting to help. Moreover, this incorrect ascription can have dangerous consequences and can lead to harm. Therefore, the practice of facilitated communication should be abandoned, because of its demonstrable inaccuracy and its potential for harmful consequences when it is utilized.

A similar claim and recommendation can be made about HA. Incorrect ascriptions of agency-related capacity can have dangerous consequences, and can lead to harm. Thus, if the cognitive mechanism of ascribing agency is deeply flawed in this way, one should abandon it. So, HA might be possible, but it is not recommended because of its potential to lead to harm. This argument has some weight, but a case needs to be made that the cognitive mechanism of ascribing agency is *severely* flawed. I will present some reasons to think that the cognitive mechanism of ascribing agency is fallible, but it has yet to be determined if it is deeply flawed.

A similar phenomenon can be observed in the well known case of the horse trainer Wilhelm von Osten and his horse Clever Hans. Clever Hans appeared to have the uncanny ability to answer questions correctly by tapping his hoof. An investigation took place about this ability and it was revealed that the trainer unconsciously signaled to Hans the answers to the questions. Unbeknownst to the trainer, von Osten had the tendency to lean forward when a question was asked and straighten up when Hans completed the correct number of taps, which allowed Hans to appear as if he was answering correctly. The trainer was convinced that his horse had a special human-like intelligence, even after the nature of his own influence was explained to him. This demonstrates that people can lose a sense of authorship for their own actions and attribute them

to agents outside themselves. Moreover, the cases of Clever Hans and FC demonstrate that we can become confused about the authorship of actions and be wrong about ascribing actions and capacities to other agents.

In “Clever Hands: Uncontrolled Intelligence in Facilitated Communication”, Daniel Wegner, Betsy Sparrow, and Valarie Fuller acknowledge that the phenomenon of incorrectly ascribing agency can be observed in collective and shared actions. They describe the phenomenon as follows:

Authorship confusion may also arise when people interpret their behaviors as collaborating with the other. People working in groups regularly experience a “we-feeling” for what the group does, such that authorship for any individual’s action is lost in the melding of individuals into the group. Individuals motivated to maintain a communal orientation may fail to record or recognize individual authorship...and so become susceptible to the projection of their own actions to other group members. (Wegner, Sparrow, & Fuller, 2003, p. 17)

If Wegner and colleagues’ claim is true, then it appears that when someone acts within a joint or collective action and forms a “we” intention, they are automatically fallible when attributing authorship to an individual’s actions. They can attribute authorship of an individual’s actions and easily be wrong about who authored the action. If HA is true, then this data implies that trustees are at risk for being fallible when they take themselves to be enabling cognitively disabled individuals.

4.3.1. A Reply to the Objection Based on the Fallibility of Trustees

In order for the data about the fallibility of trustees to be a serious problem for an HA theorist, a stronger claim needs to be made about the fallibility of the trustees. Not only must the

trustee be fallible when attributing decision-making capacities to the cognitively disabled individual, they must be systematically wrong. In sum, the trustees need to be wrong most of the time. If they are wrong most of the time, then one can argue that most people have a systematic cognitive weakness of detecting and ascribing agency and decision-making capacities to others. This systematic cognitive weakness would then create enough room to argue that the cognitive weakness is such a danger that it is a hopeless endeavor to attempt to enable a cognitively disabled person in the way described by HA. But, it is doubtful that there is enough data to suggest that for all collective decision making, when we ascribe agency to others, we are wrong most of the time.

However, suppose that there is enough data to conclude that we are all systematically defective when ascribing agency to others in shared actions. We can still press the objector to come up with a better account for when an agent helps or enables another. One might suggest extended agency theory as a better alternative, but it too would be susceptible to a similar objection. Moreover, there are a number of other objections and worries associated with extended agency that cast it in immediate doubt. In the absence of a better theory, one would have to reluctantly embrace HA as the best theory available for describing when a trustee helps a cognitively disabled person make decisions.

The phenomenon observed when one incorrectly ascribes agency to another can only be understood if we already embrace something like an account of shared agency. We observe and understand the “cognitive weakness”, when we happen to form a “we” intention and act together. We already embrace the metaphysical account of acting together to explain the phenomenon of fallibly ascribing authorship of actions to another. Without the ontological account of shared agency, we would not have a full understanding of the phenomenon in question. Similarly, to understand what happens when we become confused about authorship, we need to understand it

as a group and social phenomenon. Rather than abandon HA in light of a trustees' fallibility, we may need to embrace it to understand when it can go awry.

Finally, with future research on this phenomenon, we may be able to decipher when one is wrong to ascribe agency to another and when one is right. This suggests that we really do not know how systematic this phenomenon actually is. As Wegner and his colleagues write:

With further research, we may learn just how often and with what effect uncontrolled intelligence leads people in daily life to play puppeteers. In the right circumstances, each of us might lead others to know what we know and do what we want—even while we fail to realize that we are pulling the strings. (Wegner, et al., 2003, p. 17)

While the fallibility of trustees is an interesting and relevant factor to HA, it has yet to be determined whether it can be a definitive objection against the HA theory. Therefore, the fact that a trustee is fallible does not create a serious philosophical problem for my thesis. It may be a complication or complexity to consider when enabling another, but it is not a valid and sound objection to the theory.

4.4. Conclusion

In this chapter, my central task was to anticipate, present, and reply to a number of objections to HA theory. However, after careful consideration, many of the “objections” turned out to be additional complications, but not sound and valid arguments against HA. Other objections might be valid arguments against HA, but it is less obvious that they are sound objections.

The first series of objections were against the premise that HA is really the best theory available to understand when a person enables or helps a cognitively disabled person. There were two types of cases that were considered. The first type of case was when a trustee may disagree

with the cognitively disabled person. This case does not threaten the truth or falsity of HA, because even in cases of disagreement, shared actions can still occur through attempting to compromise. Hence disagreement does not imply that HA theory is false. The second type of case includes persons with such severe impairment that they cannot contribute to the decision in any meaningful way. This case had some relevance for HA theory, but there are some features that need to be considered. For example, one might reflect on who the person was in the past, and in this sense, acknowledging past persons might allow one to incorporate the person's past beliefs and desires into the action. However, if this is not possible, then a more paternalistic model might be appropriate. But, again, this does not imply that HA is false.

The second objection that was considered was related to impairments observed in autism spectrum disorders. The impairments related to autism can frustrate attempts to participate in shared actions. An impairment that frustrates attempts to participate in shared actions is difficulty in forming appropriate intentions for acting jointly or cooperatively. A second impairment may affect one's ability to communicate. This implies that it can frustrate attempts to communicate to the person one is acting within a joint action. A second impairment related to autism is the inability to empathize or identify with the subjectivity of others, which makes it difficult to mutually respond to another. Since the HA theorist understands a helped action as a shared activity, impairments that are encountered with autistic individuals may frustrate attempts to enable them. In reply, I argue that autism does pose a challenge to enabling another, but this does not imply that HA is false. When attempting to provide care for autistic individuals one is faced with unique challenges related to their disorder. Understanding caring or enabling within the framework of HA allows us to understand the unique care challenge that one can encounter when providing care for autistic individuals.

The third and final potential objection was based on the fact that trustees are fallible when they ascribe agency or decision-making capacities to others, when acting in groups of two or more people. Facilitated communication is an example of when a facilitator assumes that they were enabling a cognitively impaired individual, when they were actually projecting communication capacities onto them. Clever Hans was another example of when someone wrongly projected capacities onto another. It appears that reliably ascribing capacities to another is necessary for actually enabling a cognitively disabled person. Hence, it can be argued that this fallibility threatens the veracity of HA. In reply to this objection, I argue that the fallibility of trustees who wrongly ascribe decision-making capacities to others must be a more systematic cognitive weakness for the objection to hold any weight. If it's more systematic, then we cannot reliably say that trustees enable cognitively disabled persons at all. However, there is not enough data to suggest that this is a systematic cognitive defect. At the very best, we can argue that one is fallible, but how fallible we are is still up in the air. Furthermore, future research may indicate when one falsely ascribes agent-related capacities and when we do not. Hence, the fallibility of trustees does not imply that HA is false, nor does it imply that it is not the best conceptual framework for understanding helped actions.

The objections that I have considered in this chapter indicate that there are a number of complexities to consider when a person helps another. The nature of one's impairment may influence whether one can participate or not. It can also add additional challenges that can be encountered when attempting to help an impaired individual. Finally, the cognitive biases that a trustee takes into a care relationship may influence whether the trustee ascribes capacities to a cognitively disabled person accurately. While these biases indicate a fallibility about what we take ourselves to be doing or whether our belief that we are enabling another is accurate, this

does not imply that HA is false. Therefore, HA still stands as a plausible, useful, and best conceptual framework for understanding the care relationships of cognitively disabled persons.

Final Conclusion and Summary

This thesis began with the goal of creating a broader framework for agency that is inclusive of persons with cognitive disabilities. The first chapter established that persons with cognitive disabilities have historically been excluded from making decisions, and their autonomy was neglected and disrespected. Rather than being integrated into society and assisted with making decisions, persons with cognitive disabilities either had their decisions made for them or were manipulated into situations that they may not have chosen. “Agency” and “autonomy” were narrowly understood as correlating with individuals exercising their intellectual decision-making capacities rather than with joint projects that people can partake in together. The social structure that can restrict or enable one’s agency was ignored. Since agency was “individualized” and since persons with cognitive disabilities are often located in environments where they are helped by caregivers and trustees who assist them in making decisions, it is not surprising that cognitively disabled persons were historically marginalized from liberties that were associated with decision-making.

In an effort to broaden agency and autonomy to include cognitively disabled persons, the second chapter explored literature that incorporated the social environment into our understanding of agency. Two models or schemas that feature in the literature on cognitive disability and agency are paternalistic models and extended mind models. Both models have their flaws. Paternalistic models overemphasize how persons without cognitive disabilities restrict the decision making powers of persons with cognitive disabilities. Extended mind models have philosophical issues related to their ontological claims. There is also the associated moral worry that if extended mind theory is true and we understand trustees as extensions of the disabled individual, then there is a risk of negating the humanity of the trustee or the cognitively disabled

person. Extended mind models risk treating caregivers, proxy decision-makers, and trustees as objects because they reduce them to the functional parts that are used by the person needing help. Rather than acknowledging the caregiver as a person with a will, biases, beliefs, well-being and intentions, extended mind theories threaten to leave central parts of the caregiver's humanity unacknowledged. A better theory of agency incorporates both the caregiver and the disabled individual into the schema with the important features of their humanity acknowledged.

The third and fourth chapters attempted to ameliorate the problems that were highlighted in the second chapter by presenting and defending a framework that interprets care relationships, and the help that one receives when acting inside them, as a type of shared agency. I call this framework "helped agency". The HA framework ameliorates the issue associated with the paternalistic model, because it expands the decision making powers of persons with cognitive disabilities to include situations where persons with these disabilities can be helped by trustees to make self-governing decisions. It also avoids worries associated with understanding care relationship within an extend mind theory because the HA theory integrates helpers as central figures of the decision-making process. This theory includes both the cognitively disabled person and the caregiver, since both characters play integral parts in decisions and actions. Thus, it is a better framework for understanding the agency and autonomy of cognitively disabled persons, and it respects the dignity of the helper and disabled individual better than other theories presented in the literature.

As a conceptual framework, HA coheres well with feminist approaches to ethics. Nel Noddings has developed and defended an approach to ethics that places care, a value traditionally associated with women, as a central virtue to ethics (Noddings, 1984). According to Noddings, ethics is about actual relationships between a person doing the caring and a person being cared for. Likewise, Eva Kittay suggests that human relationships are often between unequal and

interdependent persons (Kittay, 1999). She valorizes actual life that people experience on an everyday basis, and that life often consists in being in a dependant relationship on others, a relationship that consists of those in need and those who can meet those needs (Kittay, 1999). Kittay's approach extends to theories about public policy to suggest that society ought to take care of and value its care workers, including mothers and those who care for disabled individuals (Kittay, 1999). If society wants to be properly functional, Kittay argues that the goal of public policy should be to empower those who care for dependents (Kittay, 1999). HA coheres well with Kittay's approach to care ethics and public policy because it acknowledges trustees and those who provide care into a conceptual framework for care in a way that does not minimize their humanity. Instead, HA theorists acknowledge the caregiver's agency, well being, intentions and autonomy as a central element in its framework. One of the first steps towards empowering those who care for dependents is to actually acknowledge their existence as human beings with their own decision-making capacities that need to be respected.

The conceptual framework of HA can also expand to encompass when the non-disabled are helped. We are all equal because we all require assistance from time to time. We all face situations where we need another's assistance to accomplish difficult tasks. When we are young, we all require the helping care that is described by HA. As we age, we may require more assistance from others when we begin to feel the corporeal effects of old age. Furthermore, with current advances in medical sciences that can extend our lives with treatments and not entirely cure us, the population of physically and cognitively disabled persons grows and changes. To embrace HA in the situations where we need help from others and provide assistance when needed is to embrace at least one aspect of how we are agents and how we are autonomous. By acting with HA as a practical guide, one can respect the dignity and autonomy of persons who may struggle to make decisions alone, and respect the dignity of those who provide care. To

acknowledge HA is to appreciate another way of being human that has been previously underappreciated: being helped to accomplish tasks and helping others to accomplish their goals. HA broadens the boundaries of agency and autonomy to encompass persons with cognitive disabilities so that policies can be formed to empower them to carry out plans of action consistent with their interests and values. With HA as an operating assumption about how persons with cognitive disabilities make decisions, policies and practices can be created so that persons with cognitive disabilities can be appropriately acknowledged and morally responded to as autonomous agents. In sum, persons with cognitive disabilities have dignity to be respected, and it is through HA that we begin to understand how we can respect it.

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