Title
Ethics and Politics of Caring and Curing: The Case of Down Syndrome and Alzheimer Disease

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Publication Date
2010

Peer reviewed|Thesis/dissertation

ETHICS AND POLITICS OF CARING AND CURING: THE CASE OF DOWN SYNDROME AND ALZHEIMER DISEASE

by

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DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF PHILOSOPHY

in

MEDICAL ANTHROPOLOGY

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

AND

UNIVERSITY OF CALIFORNIA, BERKELEY

[redacted]

ACKNOWLEDGMENTS

No anthropological project would be possible without the people who participated in making it. I am indebted to those who spent time with me in interview and conversation, and who let me in to observe their meetings and other collaborations. In equal measure, I am indebted to my academic mentors, who witnessed me through my intellectual process and catalyzed all sorts of lessons, intended and unintended. Among these, I am especially grateful for the insights and friendship of Patrick Fox, Co-director of the Institute for Health and Aging at the University of California San Francisco, who served as my dissertation committee Chair. His constant encouragement made an important conceptual space for doubt, confusion, and creativity. I could not have designed a better mentor for my research process.

In addition to Patrick Fox, I have appreciated the other members of my dissertation committee to a great extent: Lawrence Cohen, University of California Berkeley; Christie Kiefer, University of California San Francisco; and Dorothy Porter, University of California San Francisco. Their unique perspectives and support sustained me throughout the research and writing adventure. However, academic support seldom ends at the boundaries of one's committee. I have been also been blessed with many others who have expressed interest in my work and helped me on my way. I include among these Vincanne Adams, Sharon Kaufman, Adele Clarke, Guy Micco, Judith Barker, and Linda Mitteness. Administrative supporters, Claire Dunne and Kimberly Bissell, organized the endless requirements of deadlines and forms. At the University of Arizona, I benefited from the mentorship of the late Theodore Koff, Mark Nichter, Ana Ortiz, and Susan Phillips. At the University of Minnesota, I enjoyed learning from Kathy Barlow, Tim

Dunnigan, and especially Professor Mischa Penn. I want to thank Paul Rabinow, University of California Berkeley, for his kind recognition of my intellectual naïveté. The late Gay Becker, with whom I worked for two years as a graduate research assistant at the Institute for Health and Aging at UCSF, encouraged my initial impulse to apply to the UCSF-UCBerkeley Joint Program in Medical Anthropology. My first meeting with her at the annual AAA meetings in 2000 was the catalyst for the doctoral challenge, and I remember her very fondly.

My doctoral coursework was supported with generous funding from the University of California San Francisco Graduate Dean's Health Science Fellowship and Regents Fellowships. The field research and writing for this project were supported by the *Agency for Health Care Research and Quality* Health Services Research and Training Program Pre-doctoral Fellowship, supported by grant number 5 T32 HS000086. My fellowship mentor, Dan Dohan, was a valuable support during the fellowship. I also benefitted from the numerous opportunities for presentation and interdisciplinary interaction this fellowship offered me.

Fellow students I met along the way enhanced my experience. I especially thank Ben Hickler, Ippolytos Kalofonos, Jennifer Liu, and Thurka Sangaramoorthy all from the University of California San Francisco and my class cohort. At the University of Arizona, I remember my colleague and fellow student Deb Wilkerson, whose integrity and stamina awed me. Her untimely death was a potent reminder to enjoy all that is.

And last but not least: family. My very impulse to education is grounded in my family's youth, when education was valued. I have my parents, and their parents, to thank for that. Recently, I have sustained support from my aunts Anne and Susan. My brother

Greg Horton, actor extraordinaire, has been my comrade in navigating our parents' respective complexities. The treasure we found was our friendship. My husband Don, with whom it has been a joy to share my life, suffered through this adventure as only a partner can - on the frontlines of care. It was he who endured the vicissitudes of graduate school with me, from uncertainty and doubt, to hope and completion.

I dedicate this dissertation to my great-aunt, Alice Schilling.

She wished for me to get an education.

Alice was my muse in the midst of uncovering what that might actually mean.

ETHICS AND POLITICS OF CARING AND CURING: THE CASE OF DOWN SYNDROME AND ALZHEIMER DISEASE

ELIZABETH GRACE POHLMAN

ABSTRACT

This anthropological project investigates the confluence of social advocacy, science, and medicine as it relates to cognitive difference or disability for two conditions: Down Syndrome and Alzheimer's Disease. Grounded in multi-sited ethnographic methods, this research includes observation and interview in laboratory and clinic, conference, workshop, residential, advocacy, fundraising, and legislative sites.

This dissertation tells two stories. The first details the emergence of cognitive enhancement for individuals with Down Syndrome. This is a relatively new endeavor for scientific study that is growing from within research on Alzheimer's Disease and its genetic risk factors. As advocates contemplate the possibility of cognitive enhancement through pharmaceutical means, their encounter with ethical concerns poses novel predicaments, potentially altering an advocacy politics previously devoted to care and change in cultural attitudes towards Down Syndrome. Drawn into this narrative is the unique pressure that prenatal testing and abortion represent in the lives of those living under the description of Down Syndrome.

The second narrative tracks new representations of Alzheimer's Disease, made possible through the activities of science and medicine and resulting from diagnosing Alzheimer's Disease at its earlier stages. This shift has led not only to the creation of more patients, and more subjects for research, but also the possibility that individuals

diagnosed with Alzheimer's Disease might represent themselves publicly. This is a sea change in the advocacy movement associated with the disease, and also carries the potential to alter advocacy politics and its commitments to curing disease.

This dissertation details the paths advocates are arguing and practicing in their pursuit of recognition and justice in these two scenes of advocacy. I explore their interactions with science and medicine, and with scientists and medical doctors. This work is important because it illuminates the continuing power of normality and competence in everyday life, and the pressures it brings to bear on those caught in its crosshairs, individuals living under descriptions associated with abnormality and incompetence.

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PROLOGUE

In 1978, at the age of sixteen, I was employed as a nursing assistant in a nursing home. I was introduced to Alzheimer's Disease through the admission of an old man to the ward who had previously been a prizefighter. We were told that he had a rare condition called Alzheimer's Disease and, because of its unique nature, we were treated to a class detailing his individual care needs.

Alzheimer's Disease was described to us as a disease about which little was known, and framed as a problem in communication. Our new patient was thought to be slow in comprehending any verbal statements made to him due to a hesitance in his neurological processes. We were warned that this was significant for us because, as a former fighter, his first response to the frustration of incomprehension was to punch his interlocutor. In fact, this much proved to be true. Urging us to protect ourselves from this likely event, we were advised to approach him slowly, speak clearly, and pause for his response in caring for him. This man was presumed to have an intact brain and memory apparatus. The obstacle the disease presented was a complex of frayed and slowed neurons that hindered communication.

I was introduced to a second patient diagnosed with Alzheimer's Disease while working in another nursing home, two years later. Again, the disease was described as rare and mysterious. However, this patient was in her fifties and confined to a large padded crib. The most visible expression of her disease was an unceasing bodily spasticity. She could not speak, but it was assumed that she comprehended the entirety of her situation. She had a brain and memory apparatus; the disruption was in her bodily state.

In both of these facilities there were ample numbers of wandering, confused and demented residents. We called them *senile* and tried very hard not to think of them as insane.

By 1982 I had left the employment of nursing homes. For fifteen years I was only peripherally interested in developments in geriatrics or gerontology. Yet, it was impossible to ignore the intensification of Alzheimer's Disease in public media. Detailed as an epidemic of memory loss, I was continually perplexed and frankly skeptical when I read about it. This was not the Alzheimer's Disease I had seen, touched, and once cared about. Nor was it the senility I had known. Senility, as I remembered it, had been interpreted by my cohort of paid caregivers as an intensification of memory and self, not of its losses.

My motivation for investigating Alzheimer's Disease is grounded in this long-term confusion about it. The cultural stakes are high in contemporary arenas of policy, science, medicine, and citizen care for those with Alzheimer's Disease or other disabilities associated with the activities of brain or mind. For Alzheimer's Disease, "apocalyptic demography" looms large in discoursing about both care and cure. Whether an anthropology of senility merely adds to the complexity or is able to slip through the conceptual delirium to clarity remains to be seen.

CHAPTER ONE: MAKING RESEARCH

Fieldwork, after all, has been defined precisely
as the use of a person as the research instrument.
Gillian Goslinga and Gelya Frank, 2007

People encounter ethical dilemmas every day. They reach for what is at hand to fashion arguments that contribute productively to their plans, projects, and strategies. In attending to individuals experiencing cognitive difference, disarray, or decline, citizen care necessarily involves at least one additional person to think, choose, and act for them. This activity increases the stakes, and the encounter with the ethical, exponentially. Often enough, that second person (or persons) is friend or family.

What does a person need? How should needs be met? Who should provide them? How does one respond to a cultural milieu where cognitive difference can result in marginalization, discrimination, or institutionalization? As friends, family, and professionals weigh in on these questions, they compose arguments formulated from the substance of previous arguments, and these gather momentum in the form of advocacy in multiple venues. The discursive tools of medicine and science, as powerful machines of governance and economies, are marshaled to cultivate legitimacy and draw down resources to those who are less able to advocate for themselves. Likewise, advocacy becomes enrolled in the production of knowledge through science and medicine.

This dissertation details the paths advocates are arguing and practicing in their pursuit of recognition and justice for those they serve, and for themselves. I accomplish this through ethnographic investigation in two scenes of advocacy, Down Syndrome and

Alzheimer's Disease. I explore their confluence in science and medicine, and with scientists and medical doctors. This work is important because it illuminates the continuing power of normality and competence in everyday life, and the pressures it brings to bear on those caught in its crosshairs, living under descriptions associated with abnormality and incompetence.

BACKGROUND

Alzheimer's Disease has a history, and a recent one. In the span of thirty years, it has moved from a status as a rare condition to the often-claimed "disease of the twentieth century." Now considered the most frequently occurring illness associated with dementia in elders, Alzheimer's Disease is located at the center of dementia study. Currently, the diagnosis occurs at earlier ages and stages of disease than it did in previous decades. With these changes have come new ways of talking and thinking about aging and old age in American society specifically, as well as in the larger global scene. The activities of scientists, clinical medicine providers, advocates, and patients have conjoined to produce the condition we now call Alzheimer's Disease.

Within this evolving collaboration, not only Alzheimer's Disease is being remade. Knowledge production in this arena potentially recalibrates the human life course as customarily perceived, from childhood to advanced old age. It may also lead to a remaking of Down Syndrome, a syndrome produced by genetic anomaly in utero, the primary condition discerned through prenatal testing, and a historically iconic image for learning disability in the United States and elsewhere. Indeed, Down Syndrome also has a history intimately linked to medical and scientific modes of thinking and intervening. In

recent decades, people with Down Syndrome have been identified as a population at risk for Alzheimer's Disease. As a result, they are increasingly being diagnosed with this condition, often when in their forties and fifties. Where these conditions meet, the confluence creates a unique prism through which to describe emergent discourses, practices, and tensions concerning human rights and citizenship. At the heart of these collaborative ventures are cultural practices and understandings of what it means to care for others and cure disease.

I investigate the social event and cultural world of Alzheimer's Disease in the United States through an experiment of comparison, rendered through the methodological and philosophical orientations of medical anthropology. I employ multi-sited ethnographic methods to explore medical, scientific, and social practices directed toward two populations perceived to be at risk for Alzheimer's Disease: older individuals and people with Down Syndrome. My research is grounded in observation and interview in laboratory and clinic, conference, workshop, residential, advocacy, fundraising, and legislative sites for a period of about eighteen months from April 2006 through October 2007.[1]

In my anthropological project, events large and small were tracked as they occurred, resulting in an ongoing invention of the project itself. I emphasized public engagements - activities talked about and enacted in public and for public consumption. How people talked about Alzheimer's Disease, its relationship to Down Syndrome, and cognitive disability were of special interest to me. I documented when people talked in

[1] This dissertation is derived from original data from a study entitled "Alzheimer's Disease in Two Populations: A Comparative Study." It was approved by the Committee on Human Research, University of California San Francisco, approval number H6150-28032.

what ways about these matters, as well as the strategies they employed in bringing their concerns to public attention. As a result, I attend to what is being made of Alzheimer's Disease and Down Syndrome today in science, clinical medicine, and social advocacy. My analysis is attuned to public representations, rather than the existential and individualized experience of these conditions. Through the comparative intersection of Alzheimer's Disease and Down Syndrome, I also detail what is being made of cognitive difference in contemporary social life, with special attention paid to governance of those with cognitive debilities and related issues of belonging and citizenship.

CHOOSING

When I attended the 2005 International Conference on Alzheimer's Disease in Philadelphia, sponsored by the Alzheimer's Association, I was surprised to learn, through many presentations, that people with Down Syndrome had Alzheimer's Disease in high numbers. Often this detail was mentioned as a bullet point item on a PowerPoint slide presentation to illustrate an argument of the potential genetic influences and causes of Alzheimer's Disease. Many stated that all people with Down Syndrome acquired Alzheimer's Disease eventually, and some stated only that people with Down Syndrome had the plaques and tangles in their brains associated with Alzheimer's Disease. At the time, I was sifting about for a dissertation research project that would relate to my interests in dementia and old age. After many times hearing what I later understood to be a foundational social fact for these researchers, I had an insight: I would study this connection between Alzheimer's Disease and Down Syndrome in a comparative frame. When I made this decision I accepted what I had heard in these presentations as truth.

Importantly, this social fact was communicated through the scientific and advocacy world primarily associated with Alzheimer's Disease.

What I learned over time, and largely through those linked in advocacy to Down Syndrome, is that the connections made between Alzheimer's Disease and Down Syndrome are not simple ones, and that there has been controversy and tension about these issues, especially among clinicians and parents working with adults who have Down Syndrome. Furthermore, the stakes for different social actors concerning this purported connection are variable. These actors are not merely clinicians and scientists, but also parents, advocates, philanthropic funders, and people with Down Syndrome. The stakes grow fiercer for advocates as extended technologies associated not with the end of life, but with its very beginnings, become the recommended standards of pre-natal care. As I will argue, new scientific knowledges growing "under the shadow of dementia" (Katz 2008) with regard to cognitive treatment or enhancement for individuals with Down Syndrome are implicated in these entanglements.

DESIGNING and DOING

I chose a multi-sited method in designing this research, grounded in the descriptions provided by George Marcus (for an introduction to multi-sited inquiry, please refer to Addendum #1). I drew together the sites, practices, people and areas of interest relevant to my questions. This research stance also generates new questions, and often requires an ongoing reinvention of the project. Through this practice, I actively drew connections between things customarily held apart.

When speaking of Alzheimer's Disease, many people describe their fears in terms of mental retardation and the stigmas accorded people thus described. However, the cultural worlds of Down Syndrome and Alzheimer's Disease and other neurodegenerative disorders are often held apart, conceptually and practically. Systems devoted to caring for people in these two situations are distinct, and motivated along differing philosophies, despite the common thread of caring for individuals thought to be vulnerable. While these individuals may encounter one another as they cycle through various systems of care, they are conceived of as different and incommensurable as social groups. This feature of the cultural landscape made this study well-suited to a multi-sited methodology.

From April 2006 through October 2007, I was a participant-observer in many sites. The sites included clinics devoted to Alzheimer's Disease or Down Syndrome, a specialty residence for people with dementia of various types, patient review meetings, and a scientific lab concerned with the genetic and neurobiological connections between Alzheimer's Disease and Down Syndrome. I also participated and observed in many advocacy venues, including Alzheimer's Disease Advocacy Day programming in Washington and Sacramento, legislative hearings, and fundraisers for people with developmental disabilities or for those with Alzheimer's Disease. I participated in dementia care conferences both regional and national, and scientific conferences attendant to new knowledge about Alzheimer's Disease. I attended national level advocacy and family conferences concerning Down Syndrome, as well as the World Down Syndrome Congress, an international coalition of advocacy for Down Syndrome. Lastly, I participated in Down Syndrome Medical Interest Group discussions where

clinicians who serve people with Down Syndrome debate their medical and social concerns for people with Down Syndrome and other developmental disabilities. Increasingly, these conversations turned on the medical needs for adults with Down Syndrome, an arena where there is little clinical expertise and very few specialty clinics nationally. In these many venues, I held casual conversations with people who have Down Syndrome, parents of those with Down Syndrome, people in early and later stages of Alzheimer's Disease, adult children of people with Alzheimer's Disease, clinicians, scientists, and carers of various types including professionals. In total, I attended 15 conferences organized at local, national, and international levels and participated in 11 events noteworthy for their advocacy and fundraising motivations. Two of these events, Town Hall Forums where people with Alzheimer's Disease talked about their experiences and challenges, were the first of their kind.

My field notes were generally written within 24 hours of the event I had observed. I divided them loosely into three types: descriptive, methodological, and diary-type entries. I developed a practice of writing focused analytic notes concerned with broad themes and emerging questions I had from my observations and participation. In addition to field notes, some of my participant observation was conducive to being audio taped. Public lectures at conferences were audio taped, and depending upon their relevance were either reviewed or transcribed for analysis. These audiotapes became especially helpful in making correlations between what was said during the conference, and my field notes of the day.

Interviews supplemented these investigations. Throughout my fieldwork period, I interviewed advocates, clinicians, and scientists. Each interviewee was chosen for their

expertise with regard to Down Syndrome, Alzheimer's Disease, or both. Many of those I interviewed fit more than one category. For example, some participants considered themselves both advocates and clinicians, or clinicians and scientists, or all three of the participant categories. No one was compensated for his or her time and all gave generously of themselves to this project. Although interviews were partially organized in themes, they were also tailored to each person's respective experiences and activities. They were conducted in a conversational style. Along the way, participants referred me to others they thought would be helpful to my project and interested in participating. This ongoing snowball style referral system, combined with an identification of key participants through literature reviews, was an important part of becoming a part of the social networks associated with my research topics.

I conducted a total of 60 interviews. They were held in the location of the participant's choosing and audio taped with the participant's permission. No one refused to be recorded in the course of this fieldwork. The interviews were held in homes, offices, hotel rooms, hotel lobbies, restaurants, and by telephone (two). Each was about an hour in length and open-ended and conversational in tone. Questions were used to jumpstart thematic discussions, but the participant followed their own trajectories of thought in the course of conversation. My practice was to follow their lead.

The default position of my research was anonymity. However, I gave the participants the choice of whether or not to remain anonymous. I made this option available because I knew that I would be interviewing people who might wish for credit for their words and their work. Most individuals chose to remain anonymous, however where participants chose otherwise, I use their actual names in this text. I have noted

when a name is not a pseudonym throughout the text. Customary citation practices are, of course, utilized in the event that I cite from a published work.

Throughout my fieldwork period and write-up, I actively tracked the flood of public media concerning Alzheimer's Disease and Down Syndrome, attending to ongoing health and science related reporting as well as the responses and commentaries of advocacy groups. Using Google News alerts, I monitored the online media that highlighted either Alzheimer's Disease or Down Syndrome. These data were used analytically to understand the relationship between what people might be saying to me in interviews or at conferences with what was being published publicly for a wider audience. Monitoring the media helped me understand what was being discussed in advocacy meetings.

Limits

All research has limits, and this project is no exception. Major limits of this study result from the choices made to focus on the activities of advocacy, as well as scientific and medical endeavors. Living under the description of Alzheimer's Disease is, of course, a much wider and varied experience than can be captured through observation of specialized groups of actors. Many people living under the description of either Down Syndrome or Alzheimer's Disease do not interact with advocacy endeavors. Although these choices enabled me to glimpse the strategic moves of those shaping the respective worlds of Alzheimer's Disease and Down Syndrome through "studying up," the practical limits of time pushed me to jettison plans to interview and engage with those who were not part of the advocacy movements (Nader 1972). Notably, and sadly, I was unable to

include those for whom representation is often most neglected: people in advanced stages of Alzheimer's Disease and those who may have Alzheimer's Disease and Down Syndrome simultaneously. Additionally, an emphasis on the advocacy scene in Down Syndrome neglects those for whom Down Syndrome has imparted significant physiological and cognitive challenges.

Corresponding to these limits is this project's emphasis on participants that enjoy a very narrow range of socio-economic status. As one astute critic has noted, this is not a study that includes poor or even working class individuals. Therefore, the marginalization spoken about in this research has more to do with a subjective sense of cultural belonging and enfranchisement than representing economic or other exclusions.

WHEN ETHNOGRAPHY BLURS

Over a decade ago, Cohen critiqued the language chosen by feminist anthropologists who described themselves in the "sandwich generation," describing themselves as busy women trying to care for both children and parents simultaneously. Cohen considered this talk an example of using tropes related to "burden" as they related to eldercare. These comments of burden were ironically positioned in texts concerning the politics of difference (Cohen 1994).

I could easily have written the comments that were the source of Cohen's critique. Over the past three years, my family sustained multiple illness and death events. In the midst of varying levels of crisis, I cared for others and was tossed and churned by their changing needs. I strategized, advocated for them, and engaged in the crossfire of difference when anxiety, defensiveness, and pathology were present. I have also felt

exhaustion, and made difficult choices in balancing care of others with care of self, nearly all of which impacted my professional activities. Being-for-others became a habit during this time, and it became increasingly more difficult to extricate myself from the work related to caring for others. As a "middle-aged" woman, whatever that might mean, the demand *to care* burst through the steady pavement of everyday life, growing like expansive weeds through my psyche. Throughout, I was positioned at the nexus of complicated tensions, role expectations, subjective stances, and politics out of which I was unable to step. This nexus had everything to do with being a daughter, a niece, a sister, a daughter-in-law and a wife. It had very little to do with being a graduate student or someone pursuing a professional goal, except for the enabling fact of the flexibility of graduate school in its later stages.

Cohen's caution is a cogent one. It is important to note and avoid the familiar discourse of "burden" that surrounds matters of old age in the United States, deployed either as an individual constraint or a political and intergenerational metaphor. However, it is equally important to remember gendered aspects of care, but especially so in the situation of cognitive difference or decline. It was through my personal encounters with matters of health and death, a blurring of ethnographic boundaries (Leibing and McLean 2007), that I came to understand these social realities. These experiences inform what I sometimes found myself seeing in my field sites. For example, while attending conferences affiliated with Alzheimer's Disease advocacy, I found myself seeing situated gendered bodies and asking these questions: Why might care for others be feminized and domestic, with cure masculinized and public? And what happens when those category sensibilities are furthered through professionalization? What does it mean to hold a

conference on dementia care attended primarily by women professionals of various types, and a conference on dementia cure that, in stark contrast, is attended primarily by men and organized differently? And furthermore, what does it mean to have both of these conferences hosted by the same organization - the Alzheimer's Association - and often planned for and attended by the same officials of that organization? In many ways, my fieldwork was enhanced by the unexpected emergency of care and advocacy. Although my analysis does not explicitly expand upon questions of epistemology and the role of the personal, or even make especially strong arguments about gender, responding to familial situations pushed me and my research around in terms of time and space. It also contributed to what amounts to my own transformation amidst professionalization. In retrospect, I would not have had it otherwise and remain grateful for all that did transpire for me in my efforts to care for others.

WRITING

Throughout this text I use the term "Down Syndrome," as opposed to "Down's Syndrome," as the label for the condition. "Down Syndrome" is the preferred term in advocacy. The National Down Syndrome Society (NDSS) states in its Preferred Language Guide that the frequently heard "Down's Syndrome" connotes ownership or possession, and does not apply because the physician who characterized the syndrome, John Langdon Down, did not have the condition (NDSS 2010). Additionally, this revision affects the use of the commonplace nicknames for Down Syndrome that relies upon the possessive, "Down's kids," "Downsies," or "Downs," all of which are construed as either slightly or strongly offensive by many advocates. Use of "Down Syndrome"

also facilitates the person-centered language preferred by this advocacy group (for example, "person with Down Syndrome"). "Down Syndrome" is in use not only by the NDSS and advocates. This is the preferred eponym on nearly all major clinic and scientific websites concerned with Down Syndrome in the United States. I also use this terminology in the spirit of utilizing the language associated with my field sites. Similarly, I use "Alzheimer's Disease" throughout the text because that is the familiar eponym for the condition in the United States, in advocacy and in medicine.[2]

Additionally, I have borrowed a convention from Emily Martin. She utilizes the phrase, "living under the description of manic depression" in her ethnography on bipolar disorder. She asserts:

> Just what people take manic behavior to be - whether it is rational, irrational, or somewhere in between - is not a given. It is a matter determined by people actively trying to place behavior, words, performance, and style in a field of meanings. To keep this issue foremost, I deliberately use the phrase "living under the description of manic depression (or bipolar disorder)" to refer to people who have received this medical diagnosis. The phrase is meant to reflect the social fact that they have been given a diagnosis. At the same time, it calls attention to another social fact: the diagnosis is only one description of a person among many.
>
> Martin 2007

The "living under the description of" phrasing expresses a lived experience that is replete with history, metaphor, medicine, and mayhem. Through language, Martin is able to avoid the problems inherent with using a medicalized diagnostic label ethnographically

[2] It has been pointed out to me that an eschewal of the possessive in conditions named after the people who identified the disease or syndrome is not universally taken up in medicine. This choice by advocates and others to do so is a very interesting one and may be a language alteration made as part of the politics of advocacy, in addition to a politics of grammar.

as well as provide a reminder that living with the label is layered with myth, meaning, and structural constraint.

In the chapters ahead, and as I explore various ethnographic examples of advocacy for Down Syndrome and for Alzheimer's Disease, I adapt Martin's language, resulting in the phrases "living under the description of Down Syndrome" or "living under the description of Alzheimer's Disease." I extend the terminology to include not only individuals with diagnoses, but also those who live "under the description" with them as advocates, parents, siblings, and friends. Choosing this enables me to move analytically past the individuality of diagnosis, towards the multiplicity of bodies involved in situations of cognitive difference. With regard to senility, Cohen has noted that "Senility is acutely attributional: it almost always requires two bodies, a senile body and a second body that recognizes a change in the first. […] The senile body emerges as a collective representation, as fact in the world" (Cohen 1998:33-34). A language that eschews both stark diagnosis and individualism captures the extent to which those living within these situations respond to historical and contemporary sociocultural realities in their effort to make both meaning and value.

CHAPTER OVERVIEW

In the chapters that follow, I will trace a narrative that details how the concepts of Alzheimer's Disease and Down Syndrome have changed over time, and some of what is being made of them now. In Chapter Two, *Making Disease*, I develop the theoretical perspective through which arguments in later chapters are made. For heuristic purposes, I outline the concepts *medicalization* and *biomedicalization*, as they have been described

and used by some social scientists and other interpreter's of medicine's effects. Although somewhat artificial, I adopt a distinction between the two that links *medicalization* with processes associated with control and *biomedicalization* with those processes associated with transformation. This distinction borrows heavily from Adele Clarke and colleagues' formulation of *biomedicalization*. Furthermore, I introduce the term *neurodiversity* as a concept to be employed analytically and beyond the scope of its use in political activism. These three concepts set the stage for subsequent chapters and provide a lens through which to understand the ethnographic data.

Chapter Two also details brief histories of both Alzheimer's Disease and Down Syndrome, outlining their emergence from earlier concepts of senility and idiocy. This quick foray in the historical literature begins to detail the social construction of these two medical and social concepts as well as the stakes for some advocates in pursuing cultural and political change. I also provide a history of the intersection of Down Syndrome and Alzheimer's Disease. These histories demonstrate that *medicalization* is itself more complicated than an effort to control, and that it has fundamentally altered the landscapes of old age and senility, on the one hand, and idiocy, on the other.

Chapter Three, *Making Human*, discusses the stakes for advocates living under the description of Down Syndrome as they are shaped by history and contemporary attitudes towards their prime constituency. Down Syndrome's originary moment as a discrete condition within the larger category of idiocy rests within race ideas of the 19th century and the practical visibility made possible by the patterned effects of the genetic trisomy. Theorists kept those who displayed these characteristics at the borderlands of the human/animal divide, pushing this group of people to either side of the divide depending

upon the needs of their argument. The uncertainty of human status plays out in contemporary advocacy politics as an ongoing effort to work towards human status for people with Down Syndrome. This issue is made concrete through the technology of prenatal testing and the spectre of pregnancy termination. Using events surrounding the American College of Obstetrics and Gynecology's revised recommendations that expands standards for pre-natal testing for Down Syndrome as a window, this chapter details where the concepts of human and human rights have traveled in contemporary public discourse with regard to Down Syndrome.

I return to Alzheimer's Disease in Chapter Four, *Making Memory*. This chapter explores the potency of the primary trope for Alzheimer's Disease: memory and its loss. I explore the uses to which memory is put in the service of advocating for Alzheimer's Disease and promoting it as a disease worthy of attention. In this chapter, I describe memory testing and diagnosis in the clinic and memory's role in cloaking the key problematization of Alzheimer's Disease: competence. Additionally, I depict the role of memory in advocacy to mediate negative attitudes surrounding old age, and to enhance public awareness and attention. This avoidance of old age comes with consequences, however, as an emphasis on memory also contributes to fostering fear. While this may be efficient in garnering attention for Alzheimer's Disease, it also produces additional negative attitudes about old age in the United States.

Chapter Five, *Making Normal*, outlines the activities associated with enhancing cognition for people with Down Syndrome over time. It details the efforts made by parents through therapies considered alternative to increase the life chances of their children. This chapter also highlights the ways that parents – as experts and as advocates

– have become the *obligatory passage point* for arbitrating how medicine and science proceed with respect to their young and adult children. However, this chapter also demonstrates that the social and cultural pressures on Down Syndrome advocacy as a community cultivates a demand for competence and normality that surpasses previous desires for achievement. As Science grows interested in enhancing cognition in people with Down Syndrome, these parents may be persuaded to emphasize a disease concept of Down Syndrome in order to experiment with cultivating normality in their children and legitimacy in the eyes of the general public.

The pursuit of a representation approaching "normal" is also underway in the advocacy associated with Alzheimer's Disease. In Chapter Six, *Making Advocates*, I describe the advocacy scene for both Alzheimer's Disease and Down Syndrome, emphasizing the style of disease-based and cure-oriented advocacy associated with the Alzheimer's Association and Alzheimer's Disease. Chapter Six discusses the new representations of Alzheimer's Disease made possible through early age and early stage diagnosis. It describes these new emerging practices in the context of an advocacy organizational structure that is total. The choice to include people with Alzheimer's Disease in advocacy rests not only on ethical arguments, but also to garner more publicity and more support for the advocacy movement.

ANTHROPOLOGICAL EXPERIMENTS

It is sometimes difficult to explain what it is that anthropologists do. I encountered this dilemma repeatedly during my fieldwork, when asked by those I was observing or interviewing what it was I thought I was doing. In the classic tradition,

anthropologists traveled to places faraway from their homes, places thought to be exotic and different. They studied what the people there did and what they said about what they did, often collecting artifacts, interviewing, and taking copious notes as they conducted their research. In contemporary anthropology, anthropologists are just as likely to be in a geographic location close to home, or in multiple locations. In this situation, they often observe things in their own first language, attempting to step out of what is culturally familiar to them to analyze it anthropologically.

Typically, anthropologists experiment with three things. First, they try to think through taken-for-granted concepts and turn them upside down, rendering the concepts foreign to those accustomed to them. In this sense, anthropologists trouble what appears to be stable and static. It is by troubling these concepts and practices that anthropologists often offer a critique. Anthropologists make problems and incite questions, often without offering solutions. In fact, the goal is often to render that which appears universal uncertain and historically specific. An example of this from my research is my inquiry into the very concepts that constitute both Alzheimer's Disease and Down Syndrome. Each of these concepts has acquired a sense of fixity in daily life. We tend to know what they mean. Anthropological inquiry questions how it is that these concepts have been produced and elaborated.

Second, and related to the first, anthropologists often seek out cultural phenomena and the people associated with them that may be unremarkable or unrecognized. As a result, their descriptions tend to seem novel to their readers. When I speak to people about my research, most are surprised when I tell them that many scientists and some clinicians assume that people with Down Syndrome sustain high risk for developing

Alzheimer's Disease. It is not common knowledge, despite the fact that this has been a foundational fact for scientific investigations into the genetics of Alzheimer's Disease for some time. Occasionally, anthropologists are describing something new, but not of their own creation. In this latter sense, anthropologists are tracking something on the social and cultural horizon, and as an attempt to describe our own or another's cultural becoming. Inherent in this work are elements of potential critique of how that becoming is going forward. These descriptions, as they are of something not yet fully formed, also rely on their uncertainty to be potent and interesting.

Third, anthropologists (and especially medical anthropologists) are often interested in people that have been marginalized. Many graduate students in anthropology enter the field with an interest in people caught in the crosshairs of race, gender, class or other power-laden relationships. This project is no exception. My interest in people identified with cognitive and behavioral difference, and the advocacy networks associated with them, is grounded in their long and respective histories of institutionalization and exclusion from general society through ageism, ableism, or both. This third aspect requires an analytical distance from the movements of political power, such that the movements of power might be better understood and critiqued.

Taken together, these three habits of anthropologists outline a field of inquiry concerned with taken-for-granted concepts, unrecognized but perhaps emerging cultural phenomena, and the politics of exclusion and inclusion. Our experimental process has far fewer constraints than does a typical scientific lab, and we have precious little control over what occurs. Thus, our experimentation is inherently improvisational and

intersubjective and our tools are our bodies and minds in motion, cognitively enhanced with audio file, computer notebook, and coding software.

If there is a usefulness to anthropology - and I like to think that there is - it is that anthropological investigation provides what Marilyn Strathern once noted as "a prism that yields different patterns as it is turned," through which one can think through how things are going, what indeed is happening, and why certain discourses, strategies, arguments, politics and desires are motivated instead of others (Strathern 1980:178). Indeed, what anthropology provides is a venue for critical thinking and argument. Anthropology often highlights new and emerging new practices and forms, but it also illuminates the limits encountered in our collective thinking and acting. In this dissertation, I attempt both of these things.

But anthropologists do more than investigate. As was once famously observed by Clifford Geertz, anthropologists *write* (Geertz 1974). What we write are stories, or more precisely a series of stories, alongside and infused with arguments and critique, a product similar to that of the novelist. Our job is to think synthetically not only through what we might have read and studied (our training) but also through what we have seen, touched, heard, and felt in the field such as we have defined it. We ground our work in empirical detail, marshaling evidence verifiable by text, observable practice, and our own experiences through fieldwork. Our stories are necessarily partial and limited in time, and yet it is through these stories told that anthropologists make life through research.

CHAPTER TWO: MAKING DISEASE

If we could do something to prevent early Alzheimer's Disease -
it'd be the same as cholesterol -
we'd maybe want to know it when kids are eight or ten.
[…] I think it will become part of pediatric screening.
Interview, clinician with research and clinical expertise in illnesses associated with dementia

But you see, Alzheimer's Disease isn't really a disease. It is a syndrome.
And it is a common pathway towards dying.
Conversation, scientist conference participant and poster presenter, International Conference on Alzheimer's Disease Madrid 2006

My cousin glanced at me across the table, following my remark that his mother's e-mails to me had become repetitive, recounting stories that I knew were not grounded in actual events. His eyes reflected worry and, briefly, filled with a watery panic. He asked tentatively, "You're worried about her, aren't you?" I nodded, for I *was* worried. His mother, my aunt and familial friend for a number of decades, seemed to be confused about things. Our interactions with one another - by phone, e-mail, or in person - did not cohere in the ways they used to do. Within moments, my cousin choked out a second question, "How hard is it to diagnose Alzheimer's?"

This impulse to Alzheimer's Disease as an explanation for social turbulence in later life is indicative of the medical reach into the experience of old age in the United States today. In the moment of my cousin's question, an actual explanation for observable changes in my aunt's conversational and cognitive style was irrelevant. The weight of his query lay in the accretion of fear, trepidation, and anxiety anchored to the disease called Alzheimer, and played out in *his* psyche as he lay awake at nights worrying over his own increasing responsibilities. I have become curious about the impulse to ask this question, and its penetration in everyday life in the United States.

As the story from the 1970's that I recounted in my *Prologue* reveals, this impulse was not always - or even relatively recently - the case. Alzheimer's Disease, as made through a massive industry of medical, scientific, pharmaceutical, residential, social service, and care labor institutional structures has become a fearsome entity, perhaps more fearsome than senile dementia ever was or could have been. A diagnosis of Alzheimer's Disease cloaks its recipient in a guise of pathology to a greater degree than individual fluctuations in memory or behavior have historically, and this is a fundamental aspect of living under its description.

Disease categories are fluid, emergent, and often change as the production of knowledge moves. Arguably, people tend to think of movement in contemporary science as forward, as progress, and as a step towards a goal of complete understanding such that the disease might be cured. This is the broad cultural milieu in which lives are lived in the United States. While throughout time people have often worked towards alleviating that which is physically painful or socially compromising, it is contemporary science that pursues knowledge in a concrete way with an eye towards progress through the identification of causal mechanisms and a treatment that fixes. Certain diseases are illusive, tricky, ever changing with such frequency that catching up to them is half the battle. Others seem to be altered as our perceptions change, and as we create new categories to accommodate the conundrums inherent in the original concepts. This latter situation is the situation of Alzheimer's Disease, which has undergone multiple iterations. Perhaps we will eventually find a cure for Alzheimer's Disease in the lab, but equally so we may find ourselves with a new set of categories proliferating from the old, leading to a politics and set of representations that meet these new needs and perceptions. Indeed,

this is my central argument: that as science and medicine shift, they cause to proliferate more disease and more patients, but on a finely graded continuum of neurodiversity that will undoubtedly have political, social, and cultural ramifications.

What we call Alzheimer's Disease is shaped as much by how it is made important (or not) as by the longevity and life expectancies of a large percentage of the population. The extent to which Alzheimer's Disease continues in importance relies on a shifting definition of it. Expanded life expectancy, regarded for much of the twentieth century as the hallmark of progress for the national population, is potentially threatened with the increasing occurrence of chronic conditions that are difficult to manage. Interestingly, while our collective longevity has been made to appear imperiled through chronic disease and other conditions, obesity and the correlated Type II diabetes discourse being one potent example, so has the disease most associated in recent decades with old age gone through yet another age grade transformation. Once perceived to be a rare event that occurred in people who were considered at pre-senile chronological ages, Alzheimer's Disease was dramatically rearranged socially and politically with its expansion to cognitive decline associated with old age. Currently, Alzheimer's Disease is being reconfigured again as an event occurring at younger ages and as a disease that can be noted at earlier stages in its course than has otherwise been. This alteration revisits the realities of cognitive change at ages considered to be young. This dismantling of demarcations by age is a very interesting and potentially productive development because of the longstanding links made between old age and cognitive decline that often enough has resulted in confusion and exclusionary practices by age. However, there are

undoubtedly other consequences of this conceptual shift as well, as will be explored in subsequent chapters.

This remaking of Alzheimer's Disease as a condition of a younger age, and perhaps all-age such that evaluation for Alzheimer's Disease could occur in a childhood visit to a pediatrician, is intimately linked to ongoing fears about other illnesses that may cut short old age and cause deaths at younger ages. This redefinition embeds Alzheimer's Disease in the imaginations and fears of people who still consider themselves and their peers to be young, or at the very least younger than old age. So long as Alzheimer's Disease is about all of us, at any time, and in "epidemic" proportions, then it will remain a powerful lobby in Washington, a multi-billion dollar enterprise, and a forceful catalyst for neurological and other research. This aspect alone makes Alzheimer's Disease an event worthy of critical appraisal.

My research began with an interest in how aging and old age is made in the United States. At the master's level, I elicited narratives of aging from people of many ages and became aware that Alzheimer's Disease had become a potent metaphor for growing older, and fraught with much angst and fear. Among participants who were of older chronological age and residing in an assisted living residence, the opportunity to tell stories was used as a way to demonstrate authority and competence in an environment replete with evaluations of function and ability (Pohlman 2001; Pohlman 2003). On the doctoral level, my interest shifted toward what Lawrence Cohen calls the anthropology of senility, with senility defined as *"the perception of deleterious behavioral change in someone understood to be old, with attention to both the biology and the institutional milieu in which such change is marked, measured, researched, and treated"* (emphasis

his, Cohen 2006; Cohen 1998). When I became aware of the links often made between Alzheimer's Disease and Down Syndrome in science, my curiosity about the connection between groups that appear to be disparate - old agers and people with lifelong cognitive disability - lead to the development of this project. Through my juxtaposition of the connections made by science, and the related practices of medicine and advocacy by those living under the descriptions of Alzheimer's Disease and Down Syndrome, I respond to Cohen's call "to put our interpretive and critical tools to work to understand what senility might be becoming" (Cohen 2006).

Both concepts, Alzheimer's Disease and Down Syndrome, reflect situations that have not always been constructed as diseases. In the case of Down Syndrome, as I will illustrate in later chapters, it is not consistently considered a disease now. Historically, each had their corollary in broader characterizations that may have been considered problematic, but not disease. Alzheimer's Disease as it is currently understood emerged from conceptualizations of old age and senility, and cognitive disarray was often thought quite natural to the general realities of aging. Down Syndrome was once submerged in the general concept of idiocy (in the 19th century and before), mental retardation (for much of the twentieth century and today), or learning disability (the preferred term in many circles today). In order to understand these historical shifts, the analytic concepts of medicalization and biomedicalization prove very helpful.

MEDICALIZATION and BIOMEDICALIZATION, NEURODIVERSITY

The concept of *medicalization*, initially proposed by medical sociologists and then enthusiastically embraced by anthropologists and other social scientists, turns on the

accretion of territory to medicine. When a situation is adopted as a medical problem, subject to the authority of medicine and tamed through treatment, the situation has been medicalized. Often enough, it might have been perceived first as a social problem: classic examples of medicalization have included hysteria, homosexuality, and alcoholism or drug abuse. Equally frequent, the shift of authority through medicalization is often made from the legal realm of criminality or perceived moral lapses, to the medical.

Medicalization has been associated with the dynamics of authority and power, and it is often analyzed through the rubric of repressive politics. Authority and power are accrued by medicine through the territorialization of medicalization, and authority is exerted over the subject patient, who is then treated. Social analysts have queried this authority, and its effects in reducing what could be addressed at the level of the collective to a problem located within the individual. They have also relied extensively on investigating the political economy of medicalization, and potential for iatrogenic effect.

One classic example in medical anthropology is an analysis offered by Michael Taussig early in his career (Taussig 1980). Utilizing the Marxian idea of reification, the reconstitution and organization of persons and experience in terms of commodity production, Taussig assesses the mystification and reduction of patients, their lives, their pain, and their diseases to the presumed objective status of cases and things to be managed and manipulated. Through the experience of the patient, he illuminates the larger structure of medical practice and suggests that reification within the commodity-structure assists in adhering guilt to disease, alienates the patient from her own knowledge of healing therapeutics, denies her the caretaking she needs and desires, and fosters passivity through direct social control mechanisms. His challenge to medicine and

to those who study it is to focus on the "clinical construction and reconstruction of a commoditized reality" (Taussig 1980:13). His case study brings larger structural concerns of political economy into the smaller-scale manipulations within the hospital.

In 2003, Adele Clarke and colleagues introduced and elaborated upon the term *biomedicalization*. In their theoretically descriptive article, they detail what they claim is a fundamental shift in how medicalization is pursued in contemporary society, with emphasis on the United States. They explicitly correlate the sociological concepts of *medicalization* with modernity and *biomedicalization* with post-modernity. The authors define biomedicalization:

> our term for the increasingly complex, multisited, *multidirectional processes of medicalization* that are today being both extended and reconstituted through the emergent social forms and practices of a highly and increasingly technoscientific biomedicine. We signal with the 'bio' in biomedicalization the *transformations of both the human and the nonhuman* made possible by such technoscientific innovations as molecular biology, biotechnologies, genomization, transplant medicine, and new medical technologies. *That is, medicalization is intensifying, but in new and complex, usually technoscientifically enmeshed ways*.
>
> (emphasis mine, Clarke et al 2003: 162)

This epochal historical story is one that should be considered carefully, and it is not the intent of my engagement with their argument to deconstruct their historical work. However, regardless of the terms one might use - *medicalization* or *biomedicalization* or both- their conceptualization and description of what is actual in the worlds of biomedicine and clinical science these days remain potent observations. In my arguments, I will take up the concepts of *medicalization* and *biomedicalization* rather than treat them historically or as a theory to which data either adheres or not. I hope to use these concepts as portals to aid understanding of what is happening within my field

sites specifically and the overall situations of both Alzheimer's Disease and Down Syndrome.

Clarke and colleagues introduce the term *biomedicalization* to describe an extension of medicalization in the contemporary scene to include a multiplicity of actors, technologies, social stratification, risk discourses and their effects. They assert that a primary aspect of biomedicalization is its ability to *transform and customize both bodies and lives*. Their emphasis on creating new ways of living and acting through *biomedicalization* is more potent than the customary uses of the concept of medicalization and a stance which resonates with the work of social philosopher Michel Foucault as well as the works of Donna Haraway and Bruno Latour (Foucault 1975; Haraway 1997; Latour 1987). The examples they offer span from individual transformations such as cosmetic surgery and living past complete heart failure, to broad institutional arrangements that can be defined as new social forms. *Biomedicalization* thus encompasses a complex range of activities, from the diagnostic practices and interactional moments of the patient-doctor encounter, through the research modalities of clinical trial that potentially leads to treatments, to the basic and clinical science underpinnings of these efforts. It also entails the related technologies of patient management, whether that patient is served in the clinic or in the home with social services or while residing in various sorts of institutional arrangements. It comprises the vast political economies supporting both science and medicine as they seek understanding, knowledge, and cures for various conditions. It includes advocacy and identity, and the potently felt necessity of disease-based advocacy within the biomedical system/assemblage in the United States. *Biomedicalization* is about how all these

practices and practitioners interact with one another, involving politics, power, populations, and individual agency.

Of special utility is Clarke et al's emphasis on *transformation* as a central ability of contemporary *biomedicalization*. In their elaboration of the concept, they argue that "*one overarching analytic shift is from medicine exerting clinical and social control over particular conditions to an increasingly technoscientifically constituted biomedicine also capable of effecting the transformation of bodies and lives*" (emphasis mine; Clarke et al 2003:165). They trace this shift through the political economy associated with what they call the U.S. Biomedical TechnoService Complex, Inc and its related processes of corporatization, privatization, and commodification combined with rapid changes in information transfer, technological, and scientific developments, risk discourses and the transfer of morality to individual choices, and shifts from normalizing individuals in populations to the customization and augmentation of those individuals largely through their own initiative. These scholars argue that *biomedicalization* is fundamentally grounded in the production of health (as opposed to the control and management of disease), stating that "health itself and the proper management of chronic illnesses are becoming individual moral responsibilities to be fulfilled through improved access to knowledge, self-surveillance, prevention, risk assessment, the treatment of risk, and the consumption of appropriate self-help/biomedical goods and services" (Clarke et al 2003:162). This inclusion of "health itself" extends the moral dimension previously associated with *medicalization* considerably. Furthermore, they argue that the processes of *biomedicalization* have "allowed for some destabilization of differences" and that biomedicine no longer relies on a model of a universal body, but manages differences

such that those associated with "race/ethnicity, sex/gender, body habitus, age, and so on can be specified." According to these scholars, differences such as these are now largely managed through biomedicine, which contributes to further biomedicalization, the quest for new disease situations as potential markets, and new social identities (Clarke et al 2003:181).

Sharon Kaufman and colleagues offer a helpful utilization of the concept. They highlight the recent extension of high-tech medical procedures into what formerly would have been considered advanced old age, a factor which once would have marked these procedures as contraindicated, arguing that this is emerging with a new ethical field of biomedicalized life (Kaufman et al 2004). Studying surgical practices associated with cardiac management, kidney dialysis, and kidney transplant as they are enacted for individuals aged 70 to 98, these scholars claim that age as a consideration is in fact disappearing from view, making feasible a social reality where there is "no normal aging" and where one can "grow older without aging" (Kaufman et al 2004: 734 and 736). They argue that these practices emerge from an ethical field where it becomes impossible to say no to medical intervention that always must be offered, regardless of age, and that this is reflective of the expanse of *biomedicalization* that pervades all of contemporary life but especially old age, where biomedicine is constructed as the only "tool" available to solve problems associated with aging. As a result, biomedicine is a powerful force shaping our understanding of aging and facilitating new ethical relations, expectations around life expectancy and experience, and transformed bodies (Kaufman et al 2004: 731).

Importantly, others have used the term *biomedicalization*. Although Kaufman et al embrace the theoretical intervention offered by Clarke et al, they also respond directly to the use of the term offered fifteen years earlier by Carroll Estes and Elizabeth Binney in their discussion of the social construction of aging in the United States. Kaufman et al attempt to reanimate *biomedicalization* within Clarke et al's model. In contrast, Estes and Binney provide an analysis of what Estes has called the "Aging Enterprise," referring to "the programs, organizations, bureaucracies, interest groups, trade associations, providers, industries, and professionals that serve the aged in one capacity or another" (Estes 1979:2; Estes 1993). They inspect this assemblage of actors and organizational agendas and discern that aging has become exceedingly biomedicalized. By this, they mean to reflect upon the dominance of the biomedical model in everything related to old age, from the clinic to the national research agendas at the National Institute of Aging (Estes and Binney 1989). Arguing that the biological sciences have become "handmaiden" to medicine by enacting their research programs through disease based modeling rather than focusing on basic science (the source of the addition of "bio" to medicalization in their analysis), Estes and Binney outline the social construction of aging in the United States as a process where aging, and old age in particular, is thought, treated, and researched solely through the lens of biomedicine (Estes and Binney 1989). This, they argue, has serious consequence for how old age is understood. For them, *biomedicalization* reduces to individual treatment that which may be societally induced (examples might include impoverishment and isolation), and positions old age as a burden, characterized by disease and inevitable decline (Estes and Binney 1989). The strength of their analysis is precisely its similarity to that posed by Clarke et al: they

emphasize the vast political economy and related structures of biomedicine as a generator of social realities that cannot be ignored.

Clarke et al distinguish their use of *biomedicalization* from Estes and Binney by pointing out that they include technoscience as a stance within their definition (Clarke et al 2003). However, a closer look reveals that Estes and Binney engage with a more classic political economic stance, one that identifies a political and economic structuration that produces a social construction that is received by those citizens who are not participating in the process. Thus, they employ a model closer to that customarily drawn for *medicalization*, one of social control. *Biomedicalization* a la Clarke et al is full of agents as individuals who utilize what is at hand to pursue their own desires and needs, however biomedicalized those may be. Their analysis involves the participatory entanglements, predicaments, and celebrations infused in those things constructed as postmodern. Despite these distinctions, however, and the fifteen-year passage of time in the academy, Estes and Binney's observations remain valuable and accurate for much of the old age experience in the United States. In order to avoid confusion, I will consider Estes and Binney's analysis of the social construction of old age in the category of *medicalization*, rather than *biomedicalization* as outlined by Clarke et al.

What may become apparent is that those more medically frail or otherwise compromised are enrolled under the rubric of *medicalization* (characterized by control) while those who have aged more "successfully" or are considered more "functional" are accorded the wider expanse of *biomedicalization* (characterized as transformation) as a palette from which to ostensibly choose. This has far more to do with the complex status of individual bodies in time (race, gender, class, somatic disability, cognitive disability)

than with the theoretical distinction between modernity and post-modernity. The extent to which the newer concept of *biomedicalization* as taken up by Clarke and colleagues reflect significantly new phenomena in the social world, or whether it simply resonates with the broader and more expansive interests of social scientists is an interesting question. Suffice it to say, however, that because my project did attempt to touch upon the complexity of multiple sites, the concept is very helpful.

Medicalization and Biomedicalization: This Project

Medicalization and biomedicalization are analytic concepts that help frame the expanding, and sometimes conflicting, role of medicine and related activities in the organization of Alzheimer's Disease and Down Syndrome. It is through these analytic frames that it becomes possible to discern relationships between seemingly disparate things. In each situation, for example, the relationship between advocacy and scientific or clinical concerns is unique, historically and practically. Understanding these relationships facilitates a recognition that living under the description of these two situations can differ greatly despite the fact that there may be similar needs accrued under the general categories of cognitive disability, difference, or decline for individuals.

The dichotomy created between the analytic terms of medicalization and biomedicalization - the distinction between control over conditions to the transformation of them - provides a useful tension through which to think the situations of Alzheimer's Disease and Down Syndrome. Both old age and cognitive or learning disability have been reshaped and remade over the course of the twentieth and now twenty-first century, with the activities of clinical medicine contributing to these changes in fundamental ways.

Assemblages of advocacy, clinical practice, scientific research, and cultural sentiments about capacity and cognition associated with both Alzheimer's Disease and Down Syndrome are implicated in the recalibration of difference and its management. The extent to which one can describe these processes as control or transformation depends largely on the way the story is told and the standpoint of the teller. I will attempt to unravel a story that leans on both control and transformation, and provide one that questions whether or not we have left behind notions of a universal and normal body.

Throughout the remaining chapters, and through my ethnographic description, I will be raising questions about the extended reach of the medical and the scientific into the lives of those living under the description of either Down Syndrome or Alzheimer's Disease, or both. Central to my concern is the extent to which the ideas and practices I describe are oriented toward control or transformation, and how they may relate to the recalcitrance or resilience of bodies and minds under physiologic and social distress. I understand the utilization of both these frames as an attempt to place the analysis at a nexus of social processes: those associated with agency, social interaction, and innovation, on the one hand, and those associated with structuration, social control, and governance, on the other.

Neurodiversity, I suggest, is an important bridge concept between the two conceptual orientations of *medicalization* and *biomedicalization.* Its value is in the descriptive quality it brings to bear on the potential outcomes of encountering and attending to embodied difference, through mechanisms of control and transformation. In employing *neurodiversity* as an analytic concept, I am borrowing it and reshaping it from its original use as deployed by activists living under the description of autism.

Neurodiversity

Neurodiversity, a term generally attributed to activist Judy Singer with regard to autism and extended to the general public by journalist Harvey Blume, draws upon existing notions of diversity in populations along continuums of gender, social race, social class, sexuality, and disability to express the idea that any given population of people also expresses diversification along a spectrum of brain capability with resulting behavior and other cognitive differences (Singer 1997; Blume 1998). Moreover, activists deploy it as liberation: the call of neurodiversity is to embrace and celebrate the reality of diversity-by-brain and to eschew stigmas typically associated with differences associated with brain or mind. For these activists, neurodiversity exists in nature and in fact, but also exerts a pressure to recognize that neurodiversity is needed and required by a given society, and that all individuals should be able to participate in that society in a way that is meaningful and valued by others. As such, it has been taken up along the line of human rights discourses (Fenton and Krahn 2007).

Neurodiversity has been used dynamically by adult activists living under the description of Aspberger's Syndrome, a diagnosis located on the autism spectrum that often characterizes individuals with the diagnosis as "high functioning" and mild to moderately affected. This group of activists has been particularly strident on the topic of cure and treatment. For them, neurodiversity is a descriptor indicating a different way of being in the world, and they often insist that people with autism not be subject to various treatments modifying the condition. Resulting from this has been ongoing argument and debate between these activists and parents who choose to pursue treatments for their

children with diagnoses on the autism spectrum, many of whom have a range of abilities that vary significantly from those commonly described for Aspberger's Syndrome. Another political statement promoting neurodiversity has been made public through a video-gone-viral produced by Amanda Baggs, a woman living under the description of autism (In My Language, located at www.youtube.com/watch?v=JnylM1hI2jc). In her video, which documents her sensory engagement with objects and sounds, she provides a written/voiceover argument subtext that politicizes the issue of language difference between autists and society. Commenting on her video, she concludes "It is a strong statement on the existence and value of many different kinds of thinking and interaction in a world where how close you can appear to a specific one of them determines whether you are seen as a real person or an adult or an intelligent person […] Only when the many shapes of personhood are recognized will justice and human rights be possible" (Baggs 2007).

Neurodiversity as a concept has recently been taken up by scholars in the burgeoning field of neuroethics, a subdiscipline of bioethics. As is typical for bioethicists, their use of neurodiversity is in the service of exploring and making claims about what should (or should not) happen in the care, treatment, and potential cure of individuals displaying cognitive and behavioral difference. In congruence with the original political use of the term by its users, their ruminations center on the particular situation of autism, its growing population, and its quality as a lifelong and identity-centered syndrome [see a special issue on Neurodiversity, Journal of Ethics in Mental Health 2(2)].

My use of the term neurodiversity is an anthropological and analytical one, intent on the pursuit of concepts that might aid in framing and understanding the phenomena of

fieldwork. My rationale for using the concept is twofold: 1.) I want to explore the possibility that, rather than a nature that is subject to medical and scientific intervention (as some activists might claim), neurodiversity is, in some arenas, partially produced through the activities of science and medicine; 2.) I aim to respond to and trouble recent commentary in the sociological and anthropological debates regarding the "neurochemical self."

First, as I will explore throughout the remainder of this ethnography, the activities of science and medicine with regard to both Alzheimer's Disease and Down Syndrome effectively produce a graded continuum of neurodiverse possibilities. This is accomplished through the production of new diagnostic categories and identification of stages of disease, as evidenced in Alzheimer's Disease clinical and scientific research. This promotes new identities and representations of the disease. With regard to Down Syndrome, cognitive enhancement pharmaceuticals are currently being pursued, a project residing resolutely "under the shadow of dementia."

Second, current commentary on the "neurochemical self" is both assistive and worthy of some critique. Nikolas Rose has explored the dynamics of what he has termed the psy disciplines and the production of self in contemporary liberal society. In earlier work, Rose detailed the ways that psy disciplines - psychology, psychiatry, and psychoanalysis - refracted through democracy and ideals of freedom, choice, and autonomy, renders a suitable subject, a docile body, and an auto-regulating self. Through these techniques, Rose has argued, "attention has gradually but decisively shifted from the prevention of maladaption to the production of normality itself" (Rose 1998:163). More recently, Rose postulates that a shift in styles of thought, particularly in biological

psychiatry, is producing a new configuration of selfhood, what he terms a "neurochemical self" (Rose 2003a; Rose 2003b). He argues:

> The deep psychological space that opened in the twentieth century has flattened out. In its new 'neurochemical' account of personhood, psychiatry no longer distinguishes between organic and functional disorders, with only the former being thought of as somatic. It no longer concerns itself with the mind or the psyche. Mind is simply what the body, what the brain, does. And mental pathology is simply the behavioural consequence of an identifiable, and potentially correctable, error or anomaly in some aspect of the brain, in its neurotransmitters, receptors and the like.
>
> Rose 2003b:9

This, he claims, is the neurochemical self, a self with a minor error (or errors), correctable largely through pharmaceutical means targeted at the molecular level, literally (Rose 2003b). He derives this analysis from his extensive studies of pharmaceutical development associated with addiction and depression. He argues that the neurochemical self reflects a shift away from an attention to deviance and reflects a shift "from normalization to correction" (Rose 2003b:16). He calls this a "mutation in the logic of the norm" suggesting that "in this molecular gaze, we may be seeing the emergence of a new way of thinking: *variation without a norm* and perhaps, even, *anomaly without abnormality*" (emphasis his, Rose 2003b). He argues that this logic, oriented around practices of vulnerabilities and susceptibilities, renders everyone potentially correctable and subsumed under medical intervention and instruction that promises health, largely through pharmaceutical means. Powerfully, Rose documents the capitalization of vitality, and the processes by which the bits and parts of molecular material are transformed into profits. Through these assemblages, he claims that biological citizenship is intensified, while the norms - of aging, of reproduction, or of social interaction - are rewritten. He argues, "Those aspects of life that were previously devalued as pathology, whose humane

treatment and welfare was a drain upon a national economy, are now vital opportunities for the creation of private profit and national economic growth" (Rose 2003b). He concludes, "For these drugs are becoming central to the ways in which our conduct is determined to be problematic and governed, by others, and by ourselves - to the continuous work of modulation of our capacities that is the life's work of the contemporary biological citizen" (Rose 2003a:59)

Rose's analysis is both provocative and troubling. Its limits are set in an analytic style that emphasizes an ideal type that, in and of itself, is directed toward something that could be described as a norm. People other than the medication's recipient initiate the correction practices noted by Rose with regard to cognitive difference or disability. This raises a host of novel ethical concerns, raising questions about who is making what decision about which self and how it might be fashioned in what way. As we will see in later chapters, parents decide for their children what types of medications their young and adult children with Down Syndrome will ingest in the pursuit of health. And with regards to Alzheimer's Disease and related dementias, there has been a long history of chemical restraint designed to fashion the behavior and selves of people experiencing cognitive disarray, especially those residing in institutions. The existence of social stigma that turns on interpretations of a whole body with its respective signs, whether that be an old aged body or a body reflecting the phenotypic patterns associated with Down Syndrome, challenges Rose's thesis that norms are disappearing with the infusion of ideas of variation subject to correction. The concept of neurodiversity bears within it the potential to consider Rose's claims, and trouble them for how they apply in the situation of certain cognitive disabilities.

IS IT ALZHEIMER'S?

> Just prior to the workshop, I went to the bathroom, where there was a line of women waiting. The woman behind me was older, tall, and red-haired and spoke with a southwestern accent. She was pulling at the waistline of her pants, and suddenly said, with a sense of urgency "I'm getting ready. Getting my pants ready." I suspected that she was referring to the need to unbutton her trousers for using the bathroom, but I was startled at what I had heard. Then she added, to confirm what I thought, "And then when I get out of the bathroom, I usually zip up after I've left the stall to save time." I thought that this was odd, and found myself wondering if she was someone with Alzheimer's Disease, suspecting that this might be possible at a conference about caring for those who were diagnosed with the condition. It seemed socially unusual to be revealing these things in the bathroom line. But, as it turns out, I discovered through subsequent conversation that she is taking care of her husband, who has been diagnosed with Alzheimer's Disease. She commented that she would like to get him into some clinical trials, then added that he had "already been in some already, but he is no longer early stage." I asked her if the trials were only for early stage Alzheimer's Disease, and she nodded that she thought so. The woman ahead of me asked her how she knew about the clinical trials and how one signed up for them. The woman said that they had just been involved in some trials at [a nearby university] and they found out about them through their newsletter.
>
> Fieldnote, Alzheimer's Association Circle of Care conference 2007

My impulse to assume a plausible medical explanation for a puzzling social interaction is not unlike my cousin's question of me, noted at the beginning of Chapter One. In order to pose the question, a biomedical story is already present and the grooves and tracks toward a biomedical diagnosis quickly traveled. In the conversation noted in my fieldnote, expressive difference translated momentarily into medical and diagnostic difference, which then receded as the conversation continued. Whether or not this individual has Alzheimer's Disease is irrelevant. What is curious and interesting is that I could think the diagnosis based upon a quick and idiosyncratic interaction, rather than

brush off the conversational moment as merely odd or puzzling to me. A part of this had to do with context – the fact of being at a conference devoted to Alzheimer's Disease – and another had something to do with assumptions about age and cognition, and their relationship to pathology. The ability to think Alzheimer's Disease reflects its power and publicity in United States society. One could argue that senility's transformation to a medical problem could have happened otherwise, or has in fact actually been otherwise in different times and places. However, it is far more interesting to understand how it became a disease of a magnitude such that it has caught so much collective attention in the United States and beyond.

A Brief History of Alzheimer's Disease as concept: A Medicalization of Senility

Auguste Deter haunted my fieldwork. Her spectre and image presaged all histories given for Alzheimer's Disease, however brief, in scientific and other lectures. Her words, elicited through patient-doctor interview and documented by Dr. Alois Alzheimer, were regularly co-opted to demonstrate a loss of self and recognition due to the neurological pathology associated with the disease. By the end of my attendance at conferences devoted to Alzheimer's Disease, I found myself muttering crankily to myself whenever I saw her image or heard her story told that the poor woman must have been turning over in her grave with all this attention. In an era when photographs were few and far between for individuals (the early twentieth century), what may have been her sole enduring photographs were the few taken to document her dementia. The most popular image – one I have chosen not to show – features a woman in what may be a nightgown with her hands clasped across her chest, her long hair out of bounds of hair clasp and disorderly,

her eyes downcast and glancing away from the camera and the photographer. Her face is deepened with wrinkles across her brow and there is a haggard look around her eyes, which have deep folds of skin. In the photo, Auguste Deter appears decidedly unraveled. In conferences associated with Alzheimer's Disease, she was often the only individual person depicted amidst the array of graphs, tables, brain images, or neurons, with the exception of an occasional photo of a person with Down Syndrome.

Within a history of senility in the United States that often enough emphasized old age and senility as a particular problem of gender associated with men, this is a curious representation. It is reminiscent of Jean-Martin Charcot's development of geriatric texts through research in the Salpetriere asylum outside of Paris in the late nineteenth century, as noted by Stephen Katz. Although Charcot's geriatric texts refer continually to the senile old person as male, his work was grounded in a large institutional population of elder, indigent, and impoverished women (Katz 1997). In contrast with the invisible research subjects associated with Charcot who provided him with embodied templates for universalized old age, Auguste Deter is visible and in plain sight everywhere. The sheer repetition of her image, through public domain access and Powerpoint production within the research community associated with Alzheimer's Disease, works to demonstrate the adjectives often associated with the disease: ravaging, devastating, a thief. As such, Auguste Deter's photograph, despite the fact that she died long ago, carries with it the sensation of a posthumous and ghostly case demonstration.

Scientist Alois Alzheimer, working with Emil Kraepelin in Germany, first identified the characteristic plaques of Alzheimer's Disease in the post-mortem brain studies of Auguste Deter, a woman he had followed clinically and who had died of

presumed neurological dysfunction. Dying in her 50's, it was hypothesized that her disease was a rare dementia. By 1910, Kraepelin had coined the disease "Alzheimer's Disease." Rob J.M. Dillmann claims that Alzheimer was not convinced that his findings related to presenile diseases or indeed, was even a distinct disease entity. Alzheimer thought it plausible that the plaques were a change concomitant with the disease process and not a cause of dementia (Dillman 2000). This commentary of uncertainty or doubt by Alzheimer himself is often cited in contemporary scientific lectures when the speaker is proposing ideas that counter current ideology within Alzheimer's Disease research circles. Dillman argues that Alzheimer's Disease was conceptualized in the midst of the mind-brain problem of the late 19th century. Kraepelin, who regarded mental disease an excellent opportunity to study parallelism in the mind-brain relation, assessed the Alzheimer's plaques as causal in the manifestation of the symptoms observed clinically. Equally importantly, Kraepelin argued that the newly discovered disease was separate from senile dementia noted in old age, a stance which reflected customary understandings of the time that linked chronological age and life course to specific diseases (Dillmann 2000). Relatedly, Fox states:

> An alternative explanation for the classification of Alzheimer's disease as a distinct entity resides in the fact that a conception of an "early" onset of senility would be contrary to the medical thinking of the time regarding senescence. Growing old itself was considered the source of inevitable organic alterations that constituted the pathological state of senescence. As such, the development of a theory, which held that a disease constituted the "early" onset of growing old, would have been untenable.
>
> Fox 1987

However, Patrick Fox also complicates this depiction of Alzheimer's uncertainty, detailing an analysis by Alzheimer three years prior to the naming of the disease that

indicates a certainty that his findings reflected a distinct disease entity (Fox 1987). Furthermore, he suggests that Kraepelin may have been doubtful that the apparent decline of August Deter was separate from senile dementia, as well (Fox 1987).

The urge to medicalize senility in the United States gathered momentum in the mid-nineteenth century alongside a burgeoning moral stigma that accrued with industrialization and broad democratization (Achenbaum 1978; Ballenger 2006). Historians describe the colonial period as a time when age was valorized as an accomplishment and evidence of a successful society, even in situations of debility and dementia (Achenbaum 1978; Ballenger 2006). Futhermore, Calvinist theological perspectives emphasized a debility in old age as evidence of one's dependence upon God (Ballenger 2006).

According to historian Tamara Hareven, as progress increasingly was defined through business and industrialization in the nineteenth century, old age and senility were viewed in light of efficiency and usefulness on the job (Hareven 1995). Increasingly, metaphors of economics and production were used in describing body processes (Martin 1988). George Beard, for example, making the first attempt at scientific inquiry into the relationship between aging and efficiency, determined the chronological ages 30-45 as the prime time of life (Hareven 1995). Emerging classifications of stages of the life course, such as childhood or adolescence, coupled with the emphasis on sentimental relationships rather than instrumental ones in family life, rendered senility as a distinct stage of life and elders as separate and anomalous (Hareven 1995; Katz 1996). Hareven argues that this distinction through senility served to provide the very boundaries and definition for adulthood (Hareven 1995). Ballenger argues that theological shifts

associated with the transitions to industry emphasized personal responsibility and de-emphasized reciprocal obligation, stating that "suffering and loss in old age were no longer a meaningful illustration of humanity's dependence on God but evidence of moral failure," setting the stage for authority over old age to accrue to medicine (Ballenger 2006).

Cohen recounts the late nineteenth century epiphany Dr. I. L. Nascher, noted often as the founder of American geriatrics, as an encounter with the ethical for medicine. Hearing from his preceptor that the complaints of an old woman were "nothing but old age," Nasher's revelation that the woman's concerns are not old age but disease catalyze the new field (Cohen 2006; Cohen 1998). According to Cohen, the ethical problem is one of voice, and a problem of listening. Cohen refers to this as the "geriatric lament:"

> The new field is organized as a lament against silence and it responds by analyzing the senescent voice into its discrete normal and pathological components. Senility, to be heard within the clinic, is split into the existential condition of "normal aging" and the purified (Latour 1999) pathology of dementia.
>
> Cohen 2006:5

Medicalization of senility emerged within the construction of senility as moral failure, and as also a situation that engenders an ethical response, from both society and medicine.

Conventional narratives internal to biomedicine cite Alzheimer's and Kraepelin's activity in the early 20th century as the Alzheimer's Disease originary point, followed by a multi-decade dearth of investigation. The 1960's, this internal narrative continues, spawned a renaissance in Alzheimer's Disease re-discovery by the biological and neurological sciences (see, for example, Growdon and Rossor 1998). Ballenger and other

historians refute this claim, noting that ongoing debates about the relationship between Alzheimer's Disease and senility, and senility and old age, were present throughout the 20th century and crucial to the development of the multidisciplinary creation of gerontology in the 1940's (Ballenger 2000; Dillmann 2000; Fox 1987; Katz 1996). Importantly, the problem of senility and of dementia was continually configured around gender, and particularly around men losing their place in society through losses, largely due to retirement and related policies. A key post WWII figure, David Rothschild, galvanized the discipline and activism in the United States regarding senility.

Moving away from biological reductionism for either AD or senile dementia, Rothschild looked toward a dialectical interplay of multiple forces – biological, psychological, and social – as cause for senile dementia. In a voice resonant with Dr. Alzheimer's earlier skepticism, Rothschild claimed that the plaques and tangles associated with Alzheimer's Disease were tissue reactions and not one disease process. After World War II, Rothschild and those who followed his work:

> …increasingly thought of modern social relations as the pathology of senility. The locus of senile mental deterioration was no longer the aging brain; instead, it was a society that stripped elderly people of the roles that had sustained meaning in their lives through mandatory retirement, social isolation, and the disintegration of traditional family ties. Bereft of any meaningful social role, the demented elderly did not so much lose their minds as lose their places in the world.
>
> Ballenger 2000:9

This stance made way for a hope for social reform and diverse disciplines aligned in a "fight against senility," looking for alternate models for aging and society, such as the concept of successful aging (Ballenger 2000; Katz 1996). These battles required a distinction between dementia, as pathology, and old age. Ballenger argues that the

construct of successful aging further pathologized and stigmatized senile dementia (Ballenger 2006).

Throughout these decades, the medical discipline of psychiatry attended primarily to those with senile dementia, and the available institutionalization was in psychiatric institutions. Ballenger argues that this was a unique burden for psychiatry. As institutions filled with elders diagnosed with senile dementia and deemed incurable, this was perceived to threaten the discipline's pursuit of authority and prestige, which rested on the ideal of successful treatment and cure (Ballenger 2006). Policy changes in the 1960's lead to the development of nursing homes, which reduced this population in psychiatric institutions (Ballenger 2006; Koff and Park 1999). Although psychiatry as a discipline is still involved in the research and evaluation of dementia as Alzheimer's Disease, the primary arbiter of assessment and treatment is neurology in the United States today. There is some speculation that the idea of a brain disease, subject to neurological assessment, carries much less stigma than a psychiatric diagnosis, such as depression (Smith 2006).

Biologically based theorizing did not disappear with the new impetus of gerontology and social reform. Neurological research in the 1960's began to catalyze research on senile dementia as Alzheimer's Disease (Katzman and Bick 2000). In 1975, Dr. Robert Katzman and Toksoz Karasu, of Albert Einstein Medical Center, published a paper that attempted to merge the concept of AD with senile dementia (Fox 2000). Katzman was the first to suggest that Alzheimer's Disease might very well be the fourth or fifth leading cause of death in the United States (Fox 2000). It has been argued that this expanded notion of Alzheimer's Disease served sociocultural and political-economic

needs in the United States, directly affecting the status and funding of scientific researchers, institutions, and various program initiatives (Ballenger 2006; Fox 2000; Fox 1989; Gubrium 1986; Herskovitz 1995).

Patrick Fox details the emergence of advocacy devoted to Alzheimer's Disease and argues the expansion to include senile dementia enabled this new social formation. Senile dementia, when labeled Alzheimer's Disease, made concrete its construction as pathologic and not inevitable to old age, a medicalization that could engender hope for its treatment, control, and possible cure. As advocacy expanded over the 1980's, activism would increasingly be associated with the disease concept of Alzheimer's Disease, rather than, for example, needs associated with caring for persons with chronic intellectual disability. Fox argues that the needs of families and caregivers, support needs that had in part galvanized the movement, were elided in favor of research funding for scientists and institutional development. Importantly, he notes that the emphasis on a singular disease distracts from larger issues, such as universal health care coverage, around which a broader constituency could be built (Fox 2000). Actively cultivated by the newly formed National Institute on Aging (NIA), advocacy surrounding Alzheimer's Disease assisted the Institute in laying claim to a disease research mission and to its legitimacy in the National Institutes of Health (NIH) (Fox 2000).

Senility has been so decidedly medicalized that, not surprisingly, calls have been made to de-medicalize both the condition and those who live under its description. Recently, challenges to the very concept of Alzheimer's Disease have been made (Whitehouse 2008; Shabahangi et al 2009). These efforts often reveal the intractability of medicalization, and the difficulties inherent in resistance to it.

For example, Peter J. Whitehouse's text, *The Myth of Alzheimer's: What You Aren't Being Told About Today's Most Dreaded Diagnosis,* attempts to intervene in the public understanding of Alzheimer's Disease diagnosis as a dread disease with ravaging consequences, claiming to offer a new approach to responding to cognitive difference and decline associated with aging. Leaning on his authority as a neurologist and longtime researcher into the mechanisms of Alzheimer's Disease, as well as drug development, Whitehouse insists that many things about the medical model of Alzheimer's Disease and its related advocacy and economy of research are very much amiss. His primary goal is to break the stranglehold that thinking in pathological terms has on the situation of dementia. Whitehouse offers an alternate term for what has been called Alzheimer's Disease, *brain aging*, in an attempt to blur and break the fiercely drawn and often artificial distinction between normal and pathological aging that has been cultivated over the twentieth and early twenty-first centuries. Although his text contains some provocative suggestions about how political and policy efforts could be better spent (examples include basic public health measures to alleviate poverty and reduce environmental hazard), Whitehouse fails in countering the medical model precisely because he invokes it at every turn, from recommending medicine as the arbiter and assessor of cognitive change, to the standard commentary about preventing or forestalling the onset of cognitive decline through better living: exercise, diet, management of chronic diseases, and intellectual stimulation (Whitehouse 2008). Through this line of thinking, Whitehouse runs the risk of invoking historical models of attributing moral responsibility to those living under the diagnosis of Alzheimer's Disease (or brain aging), an example of de-medicalization that may also re-moralize. Whitehouse accomplishes his challenge,

in part, through a continual invocation throughout his text of his own authority and insider status to what has been termed the Alzheimer's Disease Enterprise (Beard 2005), replete with consultant fees from pharmaceutical companies.

As I have shown in this discussion, senility has undergone a steady evolving relationship to medical thinking that to a great extent is refracted through cognitive difference or change and its categorization as Alzheimer's Disease. I hope I have made clear that the urge to ask, "Is it Alzheimer's?" in response to idiosyncratic social interaction is a historically specific and constructed social reality. In the next section, I will explore similar medicalization processes accruing for Down Syndrome.

WHAT IS DOWN SYNDROME?

When people are asked, "What is Down Syndrome?" they begin their answers with startling regularity, whether they are advocates, clinicians or other service providers, or scientists. First, they state that Down Syndrome results from having an extra chromosome. This fact is often stated as if one is duty-bound to foreground it; what happens next in their responses can vary greatly from one another, but an answer that first defines genetic cause seems to be nearly compulsory. In all of my interviews that concerned Down Syndrome, I asked this question and without exception the genetic explanation for the situation that is called Down Syndrome was invoked first. This is not surprising, given the preponderance of the explanation in all informational materials, public media representations, and advocacy campaigns regarding Down Syndrome in the United States and elsewhere. It also reflects the infusion of the biomedical and the scientific throughout many aspects of living under the description of Down Syndrome.

Later, in Chapter Three, I will explore the utilization of a genetics discourse in advocacy and its perceived power to legitimate those who have Down Syndrome in the society of the United States. But for now, it is enough to notice its habitual use.

In about 95% of all cases of Down Syndrome, every cell in the body has an extra 21st chromosome. There are two other forms of Down Syndrome but both are thought to be rare, comprising 2-5% of all cases. The acquisition of the extra chromosome occurs in utero, and during cell division. With the exception of one of the rare forms of Down Syndrome, translocation, transmission of Down Syndrome is not considered hereditary.

Scientists that investigate the mechanisms associated with this genetic situation have often hypothesized that the phenotypic and medical effects of trisomy are due to overexpression, a too-muchness of genetic substance that overproduces proteins that then have various effects on the body. These excesses are often thought to be causal for the physical and cognitive differences that people with Down Syndrome display and experience. Genetic trisomy, hypothesized in this way, is fundamentally a situation of excess. Contemporary genetic sciences such as epigenetics hold the potential for troubling this theory. However, with regard to the connections and theorizations of why it is that people with Down Syndrome might be at risk for Alzheimer's Disease this theory of excess and overproduction still holds a key, and primary, theoretical position.

By far the steepest learning curve for me throughout my preparation and fieldwork was to learn of the many apparent effects of extra chromosomal material. I had not encountered many individuals with Down Syndrome during my youth, as it was characterized by a segregated special education system, or in my adult life. As a result, my impression of what Down Syndrome might be was centered on notions of learning

and cognitive disabilities, otherwise known as mental retardation. This reflected what I suspect is a general lay perception of Down Syndrome in the United States, even now in an era of inclusive education enacted in many schools. I was completely unaware of the myriad of physiological difficulties that are now medically treated in babies, children, and adults with Down Syndrome prior to developing my research project. These problems are wide-ranging, but include heart anomalies and conditions, hypothyroidism, leukemia, digestive ailments and celiac disease, strong susceptibility to life-threatening pneumonia throughout life, and a host of other medical issues with potentially serious health consequences. Heart surgery is so common for infants and children with Down Syndrome that an "anatomically correct" doll that depicts the physical patterns of Down Syndrome also sports an open-heart surgery scar (see Downi Creations, www.downicreations.com). Importantly, and despite these efforts to create a marketable and typical toy, the physiologic and variability of this condition is also very wide, with individuals born who have little to no extreme health conditions to those who experience treatment for many of them.

Given this, one could interpret Down Syndrome as a total body phenomenon, and yet the understanding of Down Syndrome primarily in terms of learning disabilities and matters of mind persists with what could be described as a peculiar tenacity. Indeed, as my fieldwork progressed, I experienced the emphasis on cognitive capacity and mind with regard to Down Syndrome strange and bewildering.

A Brief History of Down Syndrome: Emerging from Idiocy

Down Syndrome is often cited as a major contributor to learning disability or mental retardation. Its conception as a distinct and natural entity was formed within the emergence of specialty asylums in England and Wales devoted to persons then called idiots or imbeciles in the mid-19th century. These types of institutions were built in a time of optimism with regard to the treatment and cure of insanity and the rehabilitation and training of those deemed cognitively deficient. Inspired by the work of Edouard Séguin of Paris who successfully trained children considered to be idiots beyond their previous capabilities, these new institutions devoted to idiocy adopted some of his training methods and, for a time, were a favored philanthropic project (Digby 1996; Wright 2001). Séguin eventually relocated to the United States, setting up shop in Massachusetts, and his work carried considerable influence in the United States as well (Trent 1994).

Dr. J. Langdon Down, superintendent of the Earlswood Asylum in the 1860's (United Kingdom), is credited for having identified the syndrome that later carried his name. Drawing from social evolutionary theory, Down theorized that those who bore the physiological characteristics now associated with Down Syndrome were evidence of regression to a race located lower on the conceived racial hierarchy of his day, and named the condition "Mongolism" or "Mongoloid Idiocy." This is discussed in more detail in Chapter Three.

Down theorized that what caused Down Syndrome was not heredity, but was congenital, and he speculated that parental tuberculosis might be a factor (Kevles 1995). His racial argument held sway for several decades (although not universally), until successfully challenged by Dr. Lionel Penrose. Utilizing statistical analysis and extensive

blood investigation, Penrose argued against Down's racial argument. Additionally, he suggested that the single causal contribution to the manifestation of Down Syndrome was likely the age of the mother. Penrose was perhaps the first to reject the name "Mongolism" in the 1930's (Kevles 1995), however it was not until 1966 that the World Health Organization officially replaced the name with "Down Syndrome" (Wright 2001). Alternatively, in France and elsewhere, the condition is called "Trisomy 21." Fiona Alice Miller has argued that this use of a term, Mongolism, that had no apparent scientific relevance was bound up in the new genetics of Down Syndrome and a quest for a biological basis for the condition (Miller 2003). The now-obscure practice of dermatoglyphics, the study of dermal patterns on hand and feet for the purposes of diagnosing Down Syndrome prior to genetic knowledge of it, was utilized to corroborate the new genetics. This technological network relied upon the older terminology and facilitated its maintenance within scientific inquiry (Miller 2003).[3]

The latter half of the 1950's were a watershed for genetic inquiry and for the conceptualization of Down Syndrome. In 1959, Jérôme Lejeune of France announced, with trepidation, his observations that there was an extra chromosome present in the smooth muscle tissue of people with Down Syndrome (Kevles 1995). Simultaneous explorations of the possibility of chromosomal anomaly, unknown to one another, were occurring in both the United States and the United Kingdom. Verification through these additional inquiries soon followed (Kevles 1995). This discovery was especially

[3] A transverse line across the palm is a common physiological characteristic of Down Syndrome. This was named a *simian* crease in the early twentieth century by Reginald Down, son of J. Langdon Down. It is still called this in the literature on Down Syndrome today. For many decades before the discovery of the trisomy, the technique of dermatoglyphics, the study of dermal patterns on hand and feet, were instrumental in the diagnosis of Down Syndrome (Miller 2003).

important for medical genetics, a young specialty, for it gave them their own "organ," an important object for legitimation in the medical sciences specialty scheme oriented to bodily organs (Kevles 1995; Miller 2003). Additionally, the model of the Down Syndrome chromosomal anomaly was used as a foundation in identifying other autosomal disorders (Miller 2003).

Importantly in the early to mid-nineteenth century United States, institutions catering to the needs of people with learning disabilities, as well as those with other somatic disabilities such as blindness or deafness, were established along an educational paradigm. By the end of the century, however, the care for individuals then categorized as idiots had been transferred from the family setting to the state, and the institutions themselves had become frankly custodial instead of rehabilitative, and often-enough built on the pre-existing asylum model. J. Langdon Down's publications, written from a pathological point of view, contributed to the placement of medical doctors as superintendents of these institutions (Trent 1994). James W. Trent chronicles the ensuing medicalization of institutions and perceptions of mental deficiencies throughout the remainder of the nineteenth and twentieth centuries, describing in detail how the professional aspirations of doctors working in institutions devoted to those with learning disabilities worked with policy processes and scientific trends to concretize their power and expertise. Increasingly, the institutions themselves grew to extremely large size. Simultaneously, the moral implications of producing individuals with learning disability was extended beyond the individual and to families through eugenics theorizations, assuring stigma and shame to those who produced these children. These doctors were generally uninvited in the world of psychiatric specialty, and they created their own

niche, cultivating parallel associations, journals, and centers of activity. Their institutions were not merely residences or medical places, but also sites of scientific investigation and the production of knowledge concerning learning disability (Trent 1994). Trent quotes a colleague of Samuel L Fels, who pursued scientific investigation within institutions with vigor: "'As far as the Training School was concerned, [Fels] made it clear that his sole interest was research. His concern with the feebleminded was not with their training and welfare, but as he frankly put it – in getting them off the earth.'" (Trent 1994).

Arguably the long history of institutionalization of those with learning or cognitive disabilities reflects a profound level of medicalization, one that equated care with control (Trent 1994). Following WWII, when abuses in large state institutions were publicized (often through the efforts of conscientious objectors who were enacting civil service through assignment to institutional labor), coupled with the growing confessional literature of parents who became increasingly more active in resisting the medical imperative to institutionalize their children, deinstitutionalization was pursued by advocates. Trent argues that "the federal policy of deinstitutionalization resulted from an ironic convergence of developments: a combination of civil-libertarian and advocacy groups joined with state officials hoping to trim the ever-rising costs of state institutions" (Trent 1994:5).

Deinstitutionalization undid a type of medicalization, but medical intervention was ultimately still necessary for life and longevity for individuals with Down Syndrome because of the many conditions associated with the syndrome. Parents, and particularly mothers, describe this tense historical relationship through their birth narratives, a narrative form that is ever-present in private conversation and in public. Mothers speak

candidly of their unhappiness with the delivery of a diagnosis of Down Syndrome, whether prenatally or at birth. Their skepticism motivates their advocacy, and there is a strong recognition of the power of medicine to pursue technologies that would end, as well as extend, life.

As more and more of the effects of trisomy are understood as distinct disease conditions subject to medical treatment, more and more has been potentially removed from the overall realities of living under the description of Down Syndrome. As heart problems, leukemias, celiac disease, thyroid disorder, etc are identified and reasonably treated, so do people with Down Syndrome live longer and, presumably, better lives. What remains symbolically potent, then, in the situation of Down Syndrome and its definition, is what has been left un-medicalized.

Arguably, until relatively recently, the brains of individuals with Down Syndrome remained largely untouched by processes explicitly associated with medicine, with the obvious exception that treating for certain conditions such as heart, thyroid, and nutritional conditions has the effect of improving cognitive possibilities. Cognitive capacity for individuals with Down Syndrome was often assumed to be a mysterious black box, too complicated to unravel completely. Matters of cognition were deferred to specialists in psychology, behavioral therapies, and education, but not explicitly taken up through medical treatment beyond somatic malady.

This is not to say that someone did not attend to concerns about cognition. For parents, the abilities associated with their child's cognitive capacity were often paramount, and a prime motivator for pursuing therapies both established and alternative.

More will be elaborated on this later in Chapter Five. For now I will turn to the connection made between Down Syndrome and Alzheimer's Disease.

DOWN SYNDROME and ALZHEIMER'S DISEASE

Dr. Thomas Beach, neurologist and internalist historian of Alzheimer's Disease, calls the relationship between Down Syndrome and Alzheimer's Disease a "natural experiment" and unique opportunity from which the science of Alzheimer's Disease has had much to learn (Beach 1993). Importantly, he argues that the event of Alzheimer's Disease presented in persons with Down Syndrome, coupled with the chromosomal knowledge of the syndrome, initiated pathological inquiry that could proceed along experimental pathways, rather than methods he aligns with history where "the sequence of pathogenetic change must often be inferred from the end results" (Beach 1993:38). This experimental alliance has pushed the genetic science of Alzheimer's Disease forward, based on the foundational "fact" of extra chromosomal material, easily located.

Beach notes that the first observational linkage between Down Syndrome and dementia was made as early as 1876, only a decade after J. Langdon Down's first descriptions and typifications of Down Syndrome. In 1929, F. Struwe also noted the presence of the plaques and tangles now associated with Alzheimer's Disease in the post-mortem brain study of a person with Down Syndrome, and thought that the plaques established a connection between tuberculosis and Alzheimer's Disease because of the associations of tuberculosis with Down Syndrome at that time (Beach 1993). Two additional observations of these types of brain lesions in persons with Down Syndrome were noted in the 1930's and 1940's, but these observations were not drawn together

until 1948 with the work of G.A. Jervis. Jervis concluded that there was a strong connection between Down Syndrome and senile dementia and that the study of Down Syndrome would make possible the identification of the cause of senile dementia (Beach 1993; Jervis 1948). This biomedical orientation to both Down Syndrome and Alzheimer's Disease was occurring simultaneously with the emergence of social gerontology and its identification of senile dementia as sociogenic in cause (Ballenger 2006; Katz 1996). Additionally, ongoing inquiries into the relationship between Down Syndrome and racial regression as well as other research associations with the idea that people with Down Syndrome had brains resembling (and regressing) to apes and chimpanzees were occupying the minds of people who conducted research on Down Syndrome.

Jérôme Lejeune's genetic discoveries and technological advances in research contributed ongoing investigation into this area, however Beach claims that the relationship between Down Syndrome and Alzheimer's Disease was not fully appreciated until the mid-1970's or later, when the literature and research on the topic increased exponentially, simultaneous with the rise in Alzheimer's Disease research generally. Researchers I have spoken with have identified a seminal article, written in 1980 by A.H. Ropper and R.S. Williams, which catalyzed research on the relationship between Down Syndrome and Alzheimer's Disease. This article reported on the post-mortem brain studies of twenty people with Down Syndrome dying after the age of 30 and noted that all of these brains had the plaques and tangles understood to be indicative of Alzheimer's Disease. The authors also noted that only a very few of these patients exhibited behavior associated with dementia in their lives (Ropper and Williams 1980). Conferences,

proceedings, and edited collections soon followed as the research on this topic boomed (Berg et al 1993; Nadel and Epstein 1992; Sinex and Merril 1982). As research into Alzheimer's Disease became increasingly associated with senile dementia and with aging, Down Syndrome was construed as model for both Alzheimer's Disease and its associated risk factor: growing old.

Interestingly, one can now attend the Alzheimer's Association scientific research conferences and not realize fully that the discussions there deal primarily with old people. Brain images stained in vibrant hues, genetic maps, and various types of flow charts elide the fact that old people are the dominant group afflicted with the condition known as Alzheimer's Disease. The discourse of Alzheimer's Disease as an epidemic and the near constant recitation of its primary risk factor as aging, something everyone is always doing, produce an effective understanding that Alzheimer's Disease is somehow about all of us, as represented by the iconic Auguste Deter. In contrast, the "people" cited most often in these presentations are "people with Down Syndrome," following the customary naming of disability states. Having revealed a foundational fact through their genetic anomaly and brain pathology, "people" with DS carry a certain status within these discussions that invariably must review the seminal research in the genetics of Alzheimer's Disease, located in the research on Down Syndrome. One leaves these conferences with the knowledge that people with Down Syndrome have plaques and tangles, and people with Down Syndrome all eventually get Alzheimer's Disease.

This, however, is contested terrain for those most deeply involved in the realities of Down Syndrome: parents, some clinicians, and other advocates. A medical clinic was developed in the early 1990's because parents of adults with Down Syndrome were

concerned that their adult children were at risk of being over-diagnosed with Alzheimer's Disease, with deleterious effects on them as individuals. These parents were afraid that behavioral changes or decline in function would not be evaluated carefully because of the high association of Down Syndrome with Alzheimer's Disease. After approximately ten years of operation, the clinic reports that the incidence rate of persons with Down Syndrome clinically manifesting Alzheimer's Disease is no greater than the rate in the general population, except that it appears to occur about twenty years earlier than those experiencing Alzheimer's Disease in old age and without the presence of Down Syndrome (Chicoine et al 1999; McGuire and Chiccoine 2006).

The Alzheimer's Association, much like researchers presenting at their sponsored scientific conferences, seem to be conversant on the subject of Alzheimer's Disease and its association with Down Syndrome. Over lunch at a conference, a professional staff member of the Alzheimer's Association interjected assertively when I was talking about my research, stating that all people with Down Syndrome are likely to get Alzheimer's Disease. He noted the genetic connection and the fact that all people with Down Syndrome "have plaques and tangles." He punctuated this by saying that the population of people with Down Syndrome is unique because "you know from birth that they will get Alzheimer's Disease if they live long enough." This seemed to fascinate everyone around the table. I kept quiet because I wanted to hear what he had to say, and also because it seemed as though it might not be politic to contradict him publicly on this issue. However, I was surprised by his certainty. He also said that the "population of Down Syndrome people was very interesting to scientists because of this genetic connection."

Similarly, at a reception during an Alzheimer's Association conference that was attended by numerous local chapter staff, I met a woman who provides information and referral. I asked her if she ever got calls from parents or others who were concerned about an Alzheimer's Disease diagnosis for someone with Down's Syndrome. She said that she had gotten only a few. She said that people with Down Syndrome do not participate in things that the chapter offers, like support groups. She said that she talks to the parents when they call, adding that all people with Down Syndrome will get Alzheimer's Disease "if they live long enough." She told a story of a mother of a woman with Down Syndrome. The mother's adult child, "had had Down Syndrome for awhile," the woman began, "she was about thirty years old. When I told her about the connection to Alzheimer's Disease and that her daughter would get it if she lived long enough, she was really mad. I gave her all the information we had. Her doctor had never told her. Needless to say, she switched doctors!"

When I commented that the prevalence rate for people with Down Syndrome and Alzheimer's Disease was somewhat controversial, saying, "some clinicians think that the prevalence rate is about the same as the general population, but that it occurs about twenty years earlier," she argued against this point vigorously. She reiterated that the information she had through the Alzheimer's Association said that people with Down Syndrome would get Alzheimer's Disease, "if they lived long enough." She told me this in the same way two more times during the course of our more lengthy conversation with her travel partner. At the end of our conversation, as we were parting, she reiterated these facts one last time and said, "And who knows, maybe with the connection we will eventually find a cure!" I learned through these small interactions that what was suspect

among some parents and clinicians associated with Down Syndrome – the inevitability of Alzheimer's Disease for those with Down Syndrome – was instead promoted by some in the Alzheimer's Association, not only as a scientific but also hopeful fact in the pursuit of knowledge that might lead to a cure.

CARING AND CURING: MEDICALIZATION DILEMMAS

When I attended my first national advocacy meeting for Down Syndrome, the National Down Syndrome Society meeting in Chicago 2005, I was thinking a lot about Alzheimer's Disease, and it's advocacy efforts. The vision statement of the Alzheimer's Association is "a world without Alzheimer's Disease" (Alzheimer Association 2010). As I walked through the elegant lobby of the conference hotel, I realized that at least half of the individuals I observed there were either children or adults with Down Syndrome. There were young adults walking or sitting together, and many family dyads or triads with parents plus young or adult child with Down Syndrome. The scene was filled with movement and activity, and smiles or laughter as people greeted one another either as old friends or in the spirit of welcome. Reflecting on what I was observing, I was stunned by my epiphany that for this advocacy group, one would never hear a correlate for the Alzheimer's Association tagline here; this advocacy movement for Down Syndrome would never be able or willing to state that they were pursuing "a vision of a world without Down Syndrome."

Aside from exposing my own naïveté in the worlds of disability advocacy, and in the advocacy specific to Down Syndrome, this realization shaped the questions I asked as I pursued fieldwork. While it will become evident in subsequent chapters that the

dichotomy I propose is simplistic, very broadly speaking advocacy associated with Down Syndrome is oriented towards a population of people living under the description of Down Syndrome (people with Down Syndrome and their families), whereas advocacy associated with Alzheimer's Disease is oriented professionally around the disease concept of Alzheimer's Disease, which is also its purported target. The former reflects a logics of care that attends not only to an entire life course but also the lived realities of families, the latter a logics of cure. Both trajectories are implicit in medicine as a practice, however economic and political power generally accrues around the logics of cure in the United States when it comes to motivating advocacy.

Caring versus Curing

My point of departure in thinking about caring and curing is Fox's article on the social history of advocacy in the Alzheimer's Disease advocacy movement. Fox argues that the political economy of health and aging rests on three assumptions: that aging is characterized by decline; that there are deserving and undeserving recipients of care services and that the deserving (in this case) are those with a diagnosis of Alzheimer's Disease and the subject of much research expenditure; and that older individuals and their respective declines are major contributors to the health care crises. These assumptions work to keep the enterprise that is Alzheimer's Disease advocacy moving towards a quest for a cure, and away from policies and culture change that might enhance the care of people with needs for assistance, regardless of whether the cause of their need is Alzheimer's Disease or something else. He notes that the powerful lobbies of science and related businesses – such as pharmaceutical companies – will see to it that their economic

interests are protected. Carers, on the other hand, remain less protected and have fewer resources to draw upon. He suggests that disease-based advocacy creates competition between various diseases, and effectively diverts national attention from other projects, such as "developing a plan for universal medical care in general, and long-term care in particular" (Fox 2000). Fox highlights the social and political power of disease concepts, medicalization, and biomedicalization. Disease categories, further enhanced by many numbers of sufferers with the diagnosis, have the potential to mobilize a complex assemblage of actors, interests, economies and technologies to push towards solving problems. However, the disease concept itself sets boundary limits around how the problem is constructed. The limits associated with the problem have the effect of limiting potential solutions, and propelling advocates towards cure, often instead of care.

In the chapters that follow, this bifurcation of political priorities will be pursued in a comparative mode between the two advocacy efforts under study here, those related explicitly to Down Syndrome and those for Alzheimer's Disease.

CHAPTER THREE: MAKING HUMAN

With the changes in care, and the understanding of some of the complications and the ability to forestall some of the complications as well as treat others, you have individuals that don't die at age one but live until they're fifty or something like that.
[…] One can wonder about whether you want to think of these people as sick!
[…] So you don't have to approach this from a medical standpoint, which it was for many years.
You can almost think of them as a different kind of human.
[…] Down's Syndrome is the clearest example, in a sense, of a different kind of human.
Interview, clinician with a forty year career in developmental disabilities.

There is something about persons with Down Syndrome that it does seem to me to be its own race.
[…] You know it's not like they're Chinese or they're African.
[…] I don't know what other category to use but race.
[…] Another tribe of people might be better, to not get burdened with the language of race and racialization.
Interview, advocate who is a sibling to an adult with Down Syndrome and Alzheimer's Disease.

Did I mention to you? In Shanghai they say that people with Down Syndrome are people with 'international faces.' I don't know that that means but it means something.
Field notes of a conversation with a scientist and key informant.

As these statements suggest, Down Syndrome provokes reflection on human difference and a struggle to find a language that seems to be a good enough fit for the differences that are observed physiologically and often made through social interaction. In the first, an experienced clinician with a forty-year history of practice specializing in developmental disabilities reflects on where medicalization ends and difference begins. The second respondent struggles with the categories one could apply to describe differences, and her musings follow an extended commentary about how people with Down Syndrome all over the world are alike one another in terms of body type, personality, and affect. The third provides a concise cultural twist on the race ideas

associated with John Langdon Down and the label of Mongolian Idiocy, coupled with an idea of sameness.

Down Syndrome was the first condition associated with cognitive or learning disability identified within a modern frame, and has a unique history and distinction among developmental disabilities. Indeed, people with Down Syndrome are often quite literally "poster children," represented on nearly all advertising for the Special Olympics and other programs associated with learning disability or mental retardation. This iconic status has only recently been challenged by the emergence and increasing diagnostic prevalence of autism. But while autism may have a large and burgeoning portion of the media space today, Down Syndrome is what many think of first when they think of developmental disability.

What can we make of this interesting historical status? And what about Down Syndrome has set it apart in this way? Historically, Down Syndrome has been intertwined in a complicated way with the concept of race in the United Kingdom, and in the United States. This stems from early observations and identification of Down syndrome by a doctor interested in both mental retardation and the anthropological debates of his day. Central to these debates were questions about what constituted humanity and questions about difference that centered on race. His theory of the causation of Down Syndrome was intimately linked to racial theorizing popular in the 19th century, and this initial theorization, although eventually debunked as actual cause, has percolated through the history of Down Syndrome, affecting how people think and talk about Down syndrome and the people they know who carry the condition today.

In this chapter, I explore what the historical medicalization and disciplinary control of the condition called Down Syndrome makes possible in advocacy. Medicalization contributes and produces discursive strategies for advocates, as will be shown through the adaptation of genetics discourse as strategy for advocacy. It also produces perceived obstacles through its frame of pathology and quest for prevention of Down Syndrome incidence, as will be evidenced through advocates' reactions to expanded pre-natal testing guidelines for Down Syndrome. Rhetorical strategies in either direction have consequences, some of which may be separate from the intentions of their users. The use of genetic discourse, for example, can result in ideas associated with either similarity or difference, being "just like us" as humans or distinctly unique as a different kind of human. Much cultural meaning-in-the-making still whirls around notions of race and the construction of embodied essential difference.

BEING AND BECOMING HUMAN

Sitting at the round table with me was a slight, spectacled man in his early thirties. As we ate lunch, we chatted. He described himself as a stay-at-home dad, and noted that this choice was made at the birth of their daughter, who has Down Syndrome. He was academically trained in the humanities, and his wife was trained in the biosciences. They discerned that her training in the biosciences was likely to have the greater earnings potential between the two of them. Their daughter, who was born with numerous health issues, was hospitalized and in critical condition for many of her early months. Through these medical experiences and their own research, they became increasingly aware that raising a child with Down Syndrome would require additional parenting effort. This

social and practical fact pushed for a decision about their respective work and careers. He stayed home. This is often the case upon the birth of a child with Down Syndrome. In a dual parent household, however, it has often been the mother who has foregone her work plans to stay at home.

He and I swapped resources, and noted various popular books about Down Syndrome. Over the course of our conversation, we began talking about the representations of Down Syndrome in these books, often of children with Down Syndrome as angels or having cosmological and pedagogical meaning for their parents. Often, the stories of children with Down syndrome often represent the children as otherworldly, arriving in families to teach or send a message to their receiving parents.

In response to what he had read in these books, the young man harrumphed loudly, and retorted, "I don't need any saints or angels. I'm working to have my daughter be human."

In what Stephen Post has called our "hypercognitive society," people with cognitive disabilities of various types are often disregarded as less than human (Post 2000). For these individuals and their advocates, asserting human status is often a first rhetorical strategy to rectify the injustice. The project of working to be and become human in the eyes of the larger world for those living under the description of Down Syndrome is perceived as paramount in advocacy.

Historically, what was called *idiocy* in the 19th century and is now called learning disability or mental retardation, was used as a model for thinking the human, defining its parameters and inspecting its limitations. This was true for other conditions associated

with disability as well. From the 18th century, investigations of blindness contributed to discourses on human perception, and investigations of deafness, to matters of language (Baynton 2001). The philosophical mechanisms through which the contemporary concept of human was forged rests to some extent on the backs of those deemed less capable in ways thought to be distinctly human. People who were categorized as idiots, which included those with Down Syndrome, were placed in and out of the human frame depending upon philosophical perspective. Sitting at the borderlands cultivated not only practices of social care and treatment in the past, but also continues to shape contemporary politics.

My interest is in understanding how it is that advocates work to construct the concept of human. This process is still most evident when concerned with issues associated with cognitive difference or disarray because of the way that, still, cognitive and reasoning capacities are anchored to ideas of human status. Embedded in the concept of human are other resonances: legitimacy, authority, and autonomy. *Human* is not merely a category, but a place in which to become over time.

In this chapter, I will be exploring the strategies surrounding attempts to invigorate the human for those with cognitive disabilities, efforts to render the human (rather than its lack) visible to the larger society. How the human is made to appear and becomes visible differs significantly between the advocacy associated with Down Syndrome and the advocacy associated with Alzheimer's Disease. Here, I will begin by detailing historical processes that shaped and continue to shape what it is like to live under the description of Down Syndrome.

Concepts of Human and Race in the 19th Century

In the 18th and 19th centuries, and in what is often called "the west," the question of what constituted "the human" was a question of great importance. In many times and places this question had been considered. However in the 19th century, with its proliferation of disciplines and technologies of observation, investigation pushed questions towards global horizons. With capital and colonial projects well in hand, the human question was tested in the larger and wider scene of the world and all its peoples. Research far and close to home was marshaled towards arguments not only of what and who human beings were, but how the creatures of the world, including humans, could and should be treated. The division between human and animal was an important distinction, affecting how an individual could be considered, evaluated, and handled. Increasingly, governance determined who was enfranchised into human status, and whether or not they were thought to be safe, interesting, or dangerous. Down syndrome, its "discovery" and definition, as well as the general status of those then called idiots, was one minor thread in this larger theme.

Down Syndrome, of all those then designated as idiots, had the physiological distinction of a patterned (phenotypic) appearance, thus making those with Down Syndrome recognizable to those who worked with and saw large numbers of people considered to be compromised in mind and intellect. Once institutions were created for this population, a select few doctors, administrators, and staff people had the advantage of seeing and knowing many individuals with similar features and conditions. In this way, people with Down Syndrome were visible to those curious about them. Down

syndrome was the first condition associated with idiocy (then), mental retardation (the term for much of the twentieth century), or learning disabilities (the often preferred term now). Visibility, as it turns out, was key to identification and definition.

In 1866, J. Langdon Down, medical doctor, superintendent of the National Asylum for Idiots in England (later known as Earlswood Asylum), and member of the Anthropological Society of London, theorized natural types of cognitive disabilities in racial terms. In so doing, he corroborated existing racial typologies, invoked emerging evolutionary theories, and to his satisfaction proved the monogenetic stance of the famed debates on the origin of races.

J. LANGDON DOWN AND HIS IDEAS

In the history of mental retardation and its hopes for effective treatment, a favored story of beginnings details the training efforts of Jean Marc Gaspard Itard with his famous trainee Victor, also known as the Wild Boy of Aveyron (see Kanner 1964; Scheerenberger 1983; Séguin 1976; Trent 1994; Tyor and Bell 1984). Found and caught outside of Paris circa 1800, Victor was initially thought to be a savage, an uncivilized person, but was later deemed to be an idiot, a "pretend" savage, by Philippe Pinel, foremost expert on mental disorders of the day (Tyor and Bell 1984). Itard, informed by the sensualist philosophy of Condillac, initially disagreed with this assessment, but subsequent to his training efforts eventually agreed that Victor was indeed, an idiot. This story reveals that in 1800, the distinction between the categories of savage and idiot was subject to assessment and somewhat clear, despite the potential for disagreement or confusion. The concept of savage in this story refers to the state of civilization,

understood as a progressive acculturated possibility for both individuals and groups. Idiocy, however, refers primarily to incapacity to learn. However, by the 1860's, with the animated flexibility of the all-encompassing anthropological concept of race, these distinctions became rather muddled. J. Langdon Down's theorizations about the causation of idiocy exemplify this trend.

J. Langdon Down's theory was published within an active decade for the discussion of idiocy and its possible causes. It marked an individual career that began modestly as a lecturer in comparative anatomy but ended in Down's reputation as the foremost expert on idiocy of his time, in the United Kingdom and in the United States where his ideas were actively discussed. Drawn to phrenology, which embraced the idea that intellectual faculties were linked to cranial features, and social evolutionary theory, Down waded into the prominent anthropological debate of the day concerning the origins of the human species and of race: the debates between monogenism and polygenism. In 1866 he formalized and lectured on his concept of "mongolian imbecility." Presented with 600 inmates to study under his watch at the Earlswood campus, he characterized the population according to his perception of their appearance in ethnic and racial terms, and according to head and facial measurements. Those who are now regarded as persons with Down Syndrome were identified not only as looking remarkably alike one another, but also resembling people from Mongolia, Mongols. Thus, he dubbed these residents Mongoloid Idiots, afflicted with Mongolism. Drawing from social evolutionary theory, Down theorized that people with Down Syndrome were evidence of regression to a lower racial state in the conceived hierarchy of races, a spontaneous reversion of individuals to earlier "pre-moderns." He argued that this atavism was proof of the monogenic argument:

all races shared a common ancestry. Furthermore, Down felt he effectively disproved polygenism, providing evidential proof of monogenism through the living bodies of these inmates (much of this story has been drawn from Gould 1996; Kevles 2004 & 1995; Wright 2004 & 2001).

Phrenology and idiocy had long been intertwined. Despite the fact that phrenology as a science had been discarded by many scientists by 1850, it continued to hold particular interest for those studying idiocy. Originating with Austrian anatomist Johann Franz Gall in 1795, phrenological theory considered the brain to be the primary organ of the mind and a composite structure, with innate and fixed faculties located in specific locations. Inspecting the bony structure of the skull was a measurement technique used to assess the capacity of individuals (Stepan 1982). Nancy Stepan has argued that phrenology was part of a progressive movement, with many of its advocates involved in social reform of many kinds. It was also taken up popularly and across class divides, with many seeking to have their heads "read." She notes that phrenology's optimistic emphasis was on the development of individual potential; once one knew one's limitations and capacities, one could engage in an improvement project based upon this knowledge. However, phrenology was also innatist and deterministic, a feature which enabled its uptake into the emergent racial science of the 19th century (Stepan 1982). Where it had been conceived possible to rank individuals by skull measurements, it quickly transitioned to ranking groups along racialized trajectories (Gould 1996; Stepan 1982). Furthermore, phrenologists argued that animals also had the ability to learn, remember, and think, an argument that muddied the division between humans and animals and influenced those who would become associated with evolutionary theory.

Related to this, phrenologists also argued for a modified "great chain of being," a hierarchical and continuous ordering of creatures in the world that had resonances with and references to older ideas (Stepan 1982). Gall had pointed to cranial anomalies among idiots as proof of phrenology's basic tenets (Wright 2004). Correspondingly, those who sought to refute phrenology took to measuring the brain weights and skulls of idiots, a practice that Séguin bemoaned as merely attacking an idea without consideration or concern for the overall situation of those under study and the utility of phrenology for their advancement [Séguin 1976 (1864)]. Despite phrenology's diminishing status in the United Kingdom by 1850, it remained a source of inspiration for those working with idiots in asylums, including Down and one of his famous mentors, John Connolly (Wright 2004).

Down's theory was an attempt to bridge phrenological and evolutionary thinking, and prove a monogenistic stance with regard to human origins, a debate argued in terms of racial groups. Wright has argued that critiques of Down's racial argument for idiocy fail to take into account the monogenistic stance he took, one that was the more liberal of his time and is the preferred explanation for human origins today (Wright 2001). However, the monogenism of his day cannot be thought of as an innocent doctrine devoted only to the "psychic unity of mankind." Monogenism was replete with the racializations that formulated the basis for polygenism as well. Throughout the 19th century, with the emergence of paleontological, geological, archaeological, comparative anatomical, and linguistic investigations, a convergence of argument, analogy, metaphor, and symbolism resulted in a reanimation of the great chain of being within science (Alter 1999; Stepan 1982; Stocking 1987). Down's stance was a racializing one, the atavism he

proposed an influence on theories of degeneration that were already emerging in the scholarship on idiocy [see Howe 1972(1858)]. As Wright has noted, theories of degeneration to a great extent fueled the eugenics movements and debates early in the 20th century.

Although noted in accounts of Down and his theory that he was a member of the Anthropological Society of London, the tenor of this organization and its effect upon his arguments is rarely discussed (see Wright 2001 and 2004 for accounts of his membership). James Hunt established this Society in 1863 in reaction to the monogenistic stance of the Ethnological Society. Hunt, a polygenist, organized this new Society along polygenist lines and it was very popular. By 1865, the Society boasted 500 members and many were not scientists (Stepan 1982; Stocking 1987). As this was the anthropological network of Down, it seems the stakes would have been high for him in charting a monogenist position, especially given that he felt his studies effectively proved it with the physical bodies of the residents of Earlswood. Given that this was a popular venue, his arguments should be understood within this arena of polygenist debate as a challenge to the Society's status quo.

Down's theory invoked a favored physiological doctrine of medical doctors with regard to idiocy, engaged with the post-Darwinian evolutionary debate, and incorporated the most prevalent style of racialization of his time. Despite this complex articulation, and the fact that it had a little something for everyone in it, Down's theory was not universally taken up. Instead, it fostered much discussion both in the United Kingdom and in the United States (Wright 2004). His ideas were published in a decade of many publications on idiocy and for those in the debates, there was much to consider. Evidence

that Africans, presumably lower on the racial hierarchy than Mongols, could bear children who appeared to have Mongolism and evidence that people living in Mongolia did not display all the cognitive characteristics of those with Mongolism yielded skepticism. However, the terms "mongoloid idiot" or "mongolism" took hold, along with the concept of atavism as it was taken up within other ideas of heredity, especially in the United States (Kevles 1995; Wright 2004).

Some scholars extended the basic concept of atavism with regard to those considered Mongoloid idiots. Maintaining the term Mongoloid, because he thought the regression to the Mongol race was persuasive, F.G. Crookshank is an example of a scholar who theorized that the regression in some "indigenous Mongols" in England was not simply to the Mongol race, but to primates. For Crookshank, this appeared to be especially true for those considered "low-grade," cognitively (Crookshank 1924). He argued that their physical characteristics, not just of head shape and size, but also of posture and other body practices, were "more simian than Mongol." Importantly, Crookshank challenged his readers to focus not on the idiocy, but on the Mongolism. Using his techniques of physical assessment, he suggested that there were many more racially regressive individuals "in our midsts" than might have originally been thought. These theories of atavism in the body politic emerged at a time when the category of the feebleminded was gaining force in the United Kingdom (Jackson 2000). This term referred largely to those whose intellectual limitations might appear mild but who were thought to be more threatening to the nation than those who were idiotic or imbecilic because of their ability to reproduce and catalyze collective degeneration (Jackson 2000).

Reginald Down, son of J. Langdon Down and following in his footsteps as an expert on idiocy, concurred with Crookshank's hypothesis and explored it on his own. He analyzed the palms of persons with Down Syndrome, and noted a pattern of one transverse line across the palm in persons identified as Mongoloid (Crookshank 1924; Wright 2004). This was described by him then, as it is today in the literature on Down Syndrome, as a *simian* crease. For many decades, the technique of dermatoglyphics, the study of dermal patterns on hand and feet, were instrumental in the diagnosis of Down Syndrome (Miller 2003). These racialized and primatized comparative anatomy techniques remained compelling enough throughout the twentieth century to convince at least one biological anthropologist and medical doctor of human atavism to primates in the 1960s (Merton 1968). Thomas Merton argues in this small text that Mongolism differed in atavistic style by human racial types, with the reversion in some cases to primates, using the genetics of the 1960's to demonstrate his claims (Merton 1968).

Internalist texts detailing Down's theory of Mongolism often describe his typology as "atypical" or "unusual," gently masking and smoothing the potent stature of the racialized ideas from which he drew his conclusions in the 19th century, as well as their tenacious animations in the contemporary (see Kanner 1964, Sheerenberger 1983 for examples of these descriptions). The surprise that race could surface in Down's discussion is registered in the comment made to me by a geneticist researching Down Syndrome: "Dr. Down, we just don't get him." Yet the concept of race in the decades of its reinvention within the emerging scientific disciplines was not solely linked to epidermalization, as it tends to be understood today, but was a concept "used to refer to cultural, religious, national, linguistic, ethnic and geographical groups of human beings"

(Stepan 1982:xvii). Scholars such as Down or Crookshank were able to see and imagine race through skull, facial, and other body measurements. What made race visible to them was not merely skin color, but whole bodies and bodily practices. This is not to say that perceptions of skin color did not play an important part; this racial discourse on idiocy is replete with the ongoing investigations of primates, their relationship to humankind as close or distant, and the gradation of races that ranked dark-skinned Africans as primitive, animal-like, childlike in cognitive capacity, and possibly primate. In this complex sense of seeing and not-seeing skin color, J. Langdon Down could refer to some of the inmates at the Earlswood Asylum as "white negroes, although of European descent"(Down, cited in Kanner 1964:97).

HUMAN OR NON-HUMAN? LIFE AT THE BORDERS

Historian C.F. Goodey argues for an understanding of the constructed quality of the concept of idiocy. He claims that the neglect of the topic of cognitive disability in historical inquiry stems from distinctions drawn by John Locke in the 17th century for the human status of idiots (Goodey 1996; Goodey 1994). Charting a position between the orthodox Calvinist concept of the elect and the position of Arminianism, which claimed that everyone had the possibility of achieving grace, Goodey argues that Locke needed a category of exclusion. The category of exclusion he chose was the idiot changeling. Goodey argues that humanists operating in the Calvinist scene needed to justify human autonomy without threatening the concept of election. They began to do so by thinking through the 'physicality' of natural ability: "Thus too they speak in new ways about differential rationality. It is no longer simply that some humans are elect, but also that

some are more intellectually able than others" (Goodey 1996:97). The idiot, defined by Locke as a brute lacking the ability to engage in abstraction, lacked a soul and, therefore, an afterlife with which anyone should be concerned. As a changeling, Locke considered an idiot to be "a psychologically distinct type and on these grounds different in species" (Goodey 1996: 96). Locke did not consider idiocy hereditary. The concept of ability, with regard to person and soul, were foregrounded and concepts of will receded in Locke's analysis. Furthermore, Locke made opposing distinctions between idiocy and madness. Whereas idiots were relegated to a more beastly animal category, Locke construed madness as excessively human and characterized by a mis-match of ideas (abstraction gone awry) rather than an incapacity for abstract thought. Thus, Goodey argues, the cognitively disabled person emerges in the consciousness of contemporary historians as a constituent of a natural category, whereas the mad are thought to be intrinsically human, and a fascinating object of study. Interestingly, Renée Descartes, perennial fall guy for medical anthropologists, linked human status to the capacity of signs or sign making. Thus, Descartes's preference was to place idiots and others with ability dilemmas on the human side of the human/animal divide (Goodey 1994).

When Jean Marc Gaspard Itard attempted to train Victor, he was experimenting with the psychological ideas of John Locke regarding the role of experience in the development of ideas, but as they had been transformed by Etienne Bonnot de Condillac. Condillac emphasized the sensorium in the cultivation of ideas and learning, rejecting the Lockean requirement for reflection concomitant with experience to produce ideas. The training of Victor, as a result, emphasized the role of the senses and of the body in cultivating ideas and learning. Although Itard was disappointed that Victor could not

apparently be transformed from savage to civilized, but was instead an idiot, he did manage to teach Victor some things and effect some changes. Subsequent efforts to train people thought to be idiots rejected the radical sensationalism of Condillac, but remained attentive to the corporeal body in inciting curiosity and will in the students. This initial move, circa 1800, began to blur the boundaries between human and non-human status that John Locke had so carefully crafted for theological and political purposes. Through Victor and other studies of cognitively disabled individuals, idiots were tentatively invited into the expansive notions of progress and transformation, albeit with deterministic understandings that they had limits through the use of phrenology.

Just as the brains, skulls, and faces of idiots had been used to investigate innate abilities and advance phrenology and physiologically based notions of humans, so were idiots used, by Dr. Down, to prove monogenism. This theoretical move positioned idiots as part of the human order of things. If one could regress to another race in a monogenist schema, then one had not managed to fall off into the void between human and animal. The concept of genealogical descent, embedded in the pre and post Darwinian debates in linguistics, philology, and biology contributed to imagining human relatedness through difference, distinction, and hierarchy, forming a new kind of global kinship for humans as one species. Correspondingly, the consequences of idiots becoming human in the typologies of their guardians may have been the emergence of hereditary claims to degeneration due to the genealogical concept. F.G. Crookshank's theory that a regression to primates was feasible, of course, tossed the category of idiot outside human range once again.

This movement in and between human statuses for idiots reveals the uses to which idiocy was put in understanding the human in the 19th century, in Europe and the United States. Constructed at the borderlines, idiots were excluded and included in the human condition, according to varying and shifting criteria. Accordingly, they proved to be useful in arguments concerning race and race origins. Assessing who was human, how and why they were human, and where they were ranked in the racial scheme of things was of paramount concern in an era where race was "everything" and a racial worldview was actively under construction (Smedley 2002; Stepan 1982). Given the stakes, fascination, and interests taken up in these matters, Down's theory of idiocy configured along racial trajectories is not at all surprising. The manner in which he has been memorialized in the annals of disciplines devoted to cognitive disabilities, as a kind and gentle humanist, is equally unsurprising when taken into account his placement of cognitively disabled persons on the human side of the equation. In many ways this commemoration requires critical assessment. At what cost were idiots made human in this way? And what has this meant for the cognitively disabled in the contemporary scene?

Disability scholar Douglas C. Baynton argues that the shared rhetoric in the maintenance and justification of inequalities in the United States turns on the question of capacity, and specifically intellectual capacity (Baynton 2001). He claims that the concept of disability is present in justifications of discrimination, but particularly in regards to unequal treatment toward racialized groups and women. This reveals the infusion and often conflation of the concepts of race and capacity. Certainly this illustrates Goodey's claims regarding the salience of Locke's formulations of humanity

through ability, but it also hinges on a century of investigation that combined matters of idiocy with matters of race, linking both to human status and, by extension, human and civil rights. Baynton notes that arguments perpetuating disenfranchisement or immigration restrictions emphasized physiologic disability and intellectual capacity. Powerfully, this style of argumentation compels those it affects, and their advocates, to refute it by asserting that the incapacity claims are untrue. Baynton states, "while disabled people can be considered one of the minority groups historically assigned inferior status and subjected to discrimination, disability has functioned for all such groups as a sign of and justification for inferiority" (Baynton 2001:34). Within the ranks of the disabled, a hierarchy along intellectual lines is perpetuated. As Eva Feder Kittay has commented with regard to mental retardation, "It is the disability that other disabled people do not want attributed to them" (Kittay 2001:557). In fighting these political battles along the trajectories of argument drawn in the historical sands for at least two centuries, those who are cognitively disabled – the idiots of yesteryear – disappear from view. If one *is* perceived to be different-by-intellect, it is enormously challenging to either claim or demonstrate the abilities entailed in notions of belonging that wrap around competence and intellectual capacity (Edgerton 1993). This is especially true if one cannot speak, as is sometimes the case for people with Down Syndrome and other developmental disabilities. This is also true for other illnesses associated with dementia, and by extension Alzheimer's Disease.

ASSERTING HUMAN STATUS

This history of shifting status along the axis of the very concept of human is a felt reality today for those living under the description of Down Syndrome – people with Down Syndrome, their parents, their siblings and other family members, their friends and advocates. The historical resonance with physiological difference and the concept of race contributes to many narratives of stares, stigma, epithets, and denigration told both privately and publicly by families of people with Down Syndrome over the course of my fieldwork . One mother repeated, in more than one conversation with me, "It's difficult to know that the world hates your child."

The uncertainty of status has promulgated a near constant assertion of humanity, worth, and value within the advocacy movement for Down Syndrome. This assertion takes many forms, two of them recounted here in this chapter. The first involves the strategic use of genetics as an explanation for Down Syndrome that emplaces people with Down Syndrome within the boundaries of natural, normal, and human variation. This rhetoric resonates with the activist use of the term neurodiversity. The second involves an ongoing assertion for the right to be born into the human world, a strategic discourse countering prenatal diagnostic technologies and practices. These assertions may come with a cost. As one multi-decade advocate commented with sadness to me, "the fact that we have to say continually that these people are valuable tells you that we're failing. You don't have an argument about whether a person has basic fundamental human value if in fact they are accorded their rights as a human being and citizen."

As noted in Chapter Two, Lejeune's identification of Down Syndrome as a situation of genetic excess, a trisomy, was a watershed moment in genetics as a young

discipline. It was also a major event in the advocacy for individuals with Down Syndrome. As the discipline of genetics unfolded, a genetical explanation could accomplish things rhetorically that other types of explanations could not. It could push some of the cultural layers associated with living under the description of Down Syndrome around. For example, blaming parents – and particularly mothers – for producing children with Down Syndrome could be reframed and discussed differently within the explanation of trisomy, and concomitant with the evolving knowledge concerning genes and their complex interactions. The next section takes up the use of genetics within advocacy in an attempt to reshape how people with Down Syndrome and their families are seen by the social world around them.

GENETICS DISCOURSE AS A STRATEGY OF ADVOCACY

World Advocacy Day

I attended a special pre-conference event, affiliated with the World Down Syndrome Congress 2006 in Vancouver Canada, entitled "World Advocacy Day." Although the conference was ostensibly an international one, the preponderance of participants at this pre-conference event as well as at the conference in general seemed to be from either Canada or the United States, and primarily of European descent. Approximately sixty people attended the pre-conference workshop, more than was expected, and represented thirteen countries in total. When the facilitator asked for a show of hands for types of participation, nearly all participants were parents, about twenty-five were also service providers, five were siblings, one was a niece of someone with Down Syndrome, and five participants appeared to have Down Syndrome. One of

the activities of the "World Advocacy Day" workshop was to assess the cultural understanding of Down Syndrome worldwide, and to do this we, the participants, collaborated and contributed to a list of countries all over the world. The participatory exercise was to write down what we knew of the knowledge of what Down Syndrome was called in those places, and how people in those places thought about it. This effort was intended to assess the level to which people in different countries were thought to be educated to contemporary knowledge about Down Syndrome. It became evident, through the discussion that ensued, that there was a high value placed on a culture or country's people to call Down Syndrome by the name, or derivation of the name, "Down Syndrome" as well as a value placed on whether it was understood to be a genetic condition or not. With each country, the facilitator prompted, "would they consider it genetic?"

Those countries that called Down syndrome by a derivative of "Mongolism" were thought uneducated and backward in their thinking. Likewise, if people had explanations of the cause of Down Syndrome that were other than the trisomic genetic explanation, they were thought to be in need of more education. At times, a distinction was drawn between what parents of children with Down Syndrome might think versus the average person on the street. This exercise demonstrated that the genetic explanation was the correct one, and all others reflected a bias or simple ignorance that was unacceptable to this group of advocates.

Trisomy

Trisomy, and specifically the trisomy of Down Syndrome, is often described as a naturally occurring phenomenon in pregnancy that occurs with some statistical regularity. In most discussions of what Down Syndrome is, on websites or educational brochures, an occurrence rate is cited, ranging from 1 in 700 to 1 in 850 births, and resulting in a range of between 350,000 and 400,000 individuals with Down Syndrome in the United States. Additionally, a statement about the age of mothers is often made that remarks on the higher potential for a child with Down Syndrome to be born to a mother over the age of 35, customarily followed by a statement noting that most children with Down Syndrome are born to women under 35 because they have more children. The first notes the naturalness of the event of trisomy on the 21st chromosome, the situation of Down Syndrome, and the second notes the incident rate for women of older age while refuting it in practical terms.

Trisomy, according to geneticists, is generally considered a lethal condition (despite the fact that it occurs with statistical regularity). They suspect, although this cannot be proven with certainty, that most pregnancies that end in miscarriage do so because of some sort of trisomy, although not necessarily the trisomy that is identified as Down Syndrome. Indeed, some children with Down Syndrome are born with life-threatening conditions and for this specialized group life can be short. Given this observation, one could also derive that infants born with Down Syndrome are already survivors, and have acquired one of the least life threatening trisomies that are known.

It is very interesting that the language of those advocating for Down Syndrome emphasize that statistical regularity is also "naturally occurring." It is an understanding

that the genes we all acquire are either a matter of luck or god and not chosen, plus the use of the meaning laden term "natural" that enables a very useful and strategic rhetoric for this group. Countering an idea of parental blame, and mitigating any idea of trisomy as pathology (often understood as unnatural), genetic explanation is seized upon as a potentially powerful tool for redefining the condition that has long undergone the layering of race ideas, denigration, societal neglect, and abuse.

Being Natural

This genetic explanation accomplishes much more politically than simply providing the cause for Down Syndrome. It is its neutrality as an explanation – scientific, commanding, and certain – that is called upon to promote a contemporary and progressive definition. Where the move from statistically regular to natural is one conceptual jump, the much more socially valuable one is the leap from being "natural" to being "normal." In the political language surrounding advocacy for Down Syndrome, normality – and the quality of being a part of "normal variation" or a "normal bell curve," are powerful constructs. This type of being natural, and therefore normal, is what firmly situates people with Down Syndrome on the human side of the historical divide between humans and non-humans, in political and human rights discourse.

It is not especially insightful to demonstrate where people are socially defined as *human*. What is worthy of note is how much work it takes to get there. This requires that advocates refute historical trends and imagery. They work *towards* becoming interpreted as human through a series of meaning-filled concepts, a language deeply connected to legitimacy and authority (often the language of science), and a serious effort to educate

such that the language of others – even those across the globe – will match up to political expectations. This takes a lot of work, and arguably the penetration and uptake of a genetics discourse enables this transformation. This is the central work of advocacy for Down Syndrome, redefining the terms such that people with Down Syndrome will be construed to be irrevocably human.

Evidence from Public Educational Campaigns

The Canadian Down Syndrome Society (CDSS) showcased their public educational advertising campaign during the World Down Syndrome Congress. These televised educational messages depicted young adults with Down Syndrome in the familiar places of school, work, and play. In these videos, young adults with Down Syndrome were interacting with those often referred to as "typically developing peers," socially networked with people who did not have Down Syndrome. In one, a young woman was with friends in the cafeteria at her community college. Each young woman was describing to the others what their major was, in what one might guess was a first day of college. One woman asked the young woman with Down Syndrome what her major was, and her response was that she was majoring in photography and art. The tagline at the end of the scene, in a narrated voiceover was "Different Genes, Same Value."

This educational advertisement communicates the idea that having different genetic material does not affect the value of the person. It also depicts individuals in typical situations of going to school, work, and interacting with peers. Although the configuration of genes is "different" for Down Syndrome (three chromosomes instead of

the usual pair), the fact of their difference, this ad is arguing, does not make the person any less valuable or any less at all.

Similarly, the National Down Syndrome Congress (NDSC), an advocacy group in the United States, promoted a video campaign that featured young adults with Down Syndrome, speaking into the camera and to the imagined video audience. Their short monologues detailed key aspects of their lives associated with work, play, and achievements. The punch line, delivered by the speaker in every video, was "We're more alike than different" (access online: http://www.youtube.com/watch?v=qVHCWJdus_4). For example, here is the text for one:

> I am [name]. I am twenty-nine years old and I have Down Syndrome. Something special just happened to me. My boyfriend asked my dad in the hand of marriage. He is wonderful! He's cute! I love him a lot. I want to be beautiful as a bride. See… we are more alike than different. [Pause] I'll have a big big wedding with three hundred people!

The tagline, "We're more alike than different," (as well as the videos themselves) remains on the NDSC website and on their promotional materials.

This is a very interesting play with words. For at least a century, folks with Down syndrome have been described as being "like" one another, more like one another than they are with their families in some cases, as the reference to their being a "tribe" in the preface to this chapter suggests. But the "we" in the "we're more alike than different" is the wider human community and references this larger community as audience. It expresses the idea that people with Down Syndrome are more like other people without Down Syndrome than they are different, producing a countering discourse to the one that emphasizes their differences-from-typical. This also plays on current discourse of genetics, which often comments directly on the very small variation between individuals

and between groups, especially regarding race and ethnicity. In invoking this, Down Syndrome advocacy is also invoking these now-common arguments about genes and difference. They are saying that folks with Down Syndrome are more human than they are different from human. Importantly, these media campaigns reflect the actual increasing numbers of people with Down Syndrome who are getting married, attending community college, living independently, and driving cars.

Just Like Us

The statement, "we're more alike than different," resonates as a theme among advocates living under the description of Down Syndrome as parents, siblings, or friends. This kind of statement is also expressed in what I call a *just like us* stance. This kind of assertion was made in interviews I conducted, many conversations, and is present in much of the public media surrounding Down Syndrome. The idea that *they* and *we* are the same is another way of saying that we are all human, and is part of the work *towards* human. As people invoke this sentiment the similarities expressed are variable. For example, a long-term advocate concerned with services and programs offered the following in response to my question, "Are there any special needs that adults with Down Syndrome have?"

> Well they have the same needs as nondisabled adults have. They need to be productive, they need jobs, and a way to earn and save. They need to live independently they need significant others in their lives, they need health care, they need long term care, transportation to get to work. I'm not sure what else - friends! A network of friends and a way to belong to a community.

This list is interesting for what it says about adults without Down Syndrome and what is perceived to be the important contours of living: work, autonomy, and

community. This advocate is also saying that, like those without Down Syndrome (us), people with Down Syndrome need an infrastructure of safety nets (medical systems) and mobility (transportation) in order to be able to access these activities. What remains unstated here is the extent to which many of these needs require explicit and conscious cultivation on behalf of the individual with Down Syndrome. Infrastructures such as transportation networks and health care systems are enacted presumably for all, however people with Down Syndrome may need accessibility to those systems (a matter often not included in their design), or in the case of medical systems a certain amount of medical expertise in the practitioner. The fact they need these things may reflect a similarity between people with Down Syndrome and those without Down Syndrome, but the lived reality that their needs may currently be unmet by the systems that exist, or that they may need differently from them remains unsaid in the effort to establish "sameness." Similarly, although it is common enough to hear that people and populations generally need jobs, sustainable wages, and other infrastructures of support, the work of friendship and a community are not customarily governed explicitly. In the case of Down Syndrome, spaces for community and friendship often need to be actively made and promoted, often enough by those who may not have Down Syndrome but share concerns about inclusion. Indeed, it is the work of the advocacy movement to make such a community for all people living under the description of Down Syndrome, and their hope to extend the possibilities of inclusion out into society.

Often enough, statements reflecting *just like us* sentiments turn on idealizations of citizenship, success within a capitalist economy, and notions of an equality that is presumed to exist for *all of us*. For instance, a conference participant and mother of three

children, one of whom has Down Syndrome, cited author and advocate John O'Brien, who with his wife Connie Lyle O'Brien has worked toward developing guidelines and programs for promoting inclusion and person-centered care for individuals with developmental disabilities. She said that she "agreed with John O'Brien," who said that the wishes of people with developmental disabilities are to be "contributing citizens and valued friends," to which she added, "that's pretty much like the rest of us."

Another media example is sponsored by the National Down Syndrome Society (NDSS) entitled "Dreams." This video features children and adults with Down Syndrome stating, or in some cases demonstrating, their accomplishments, pride, and dreams for their future. Mia Peterson, self-advocate and (then) member of the Board of Directors of the NDSS, introduces the video with the statement that "Everyone has dreams, including people with Down Syndrome." Later, she comments, "Someday, all people with Down Syndrome will be able to achieve their dreams." Participants state that they are proud of being a Girl Scout or Eagle Scout, making the honor roll, living on their own, being an artist, or being an advocate. Dreams for the future turn on classical cultural themes in the United States: going to college, running for President, becoming a doctor, or driving. One young adult states, "I like making money, so I can buy the things I love."

Or, in a workshop I attended, the leader talked about her adult son Pete, noting that the labels attached to him had changed over time: mentally retarded, developmentally disabled, with Down Syndrome, intellectually disabled. She quickly rattled off all the diagnostic and quasi-diagnostic possibilities, concluding that "but mostly, he's just Pete." She added that Pete "lived independently, worked his dream job,

and if asked, would say that he owns his own home." She paused for a beat and then smiled, saying somewhat conspiratorially, "But we really own it."

These kinds of statements provoked this kind of musing for me in my fieldnotes:

> After a long wait, the performance finally began with a speech from a representative of the Canadian Down Syndrome Society. He said, "we value all genes equally" and emphasized the promotion of inclusion in all advocacy endeavors. He said that people with Down Syndrome should have all the opportunities that "everyone else" has, to be "just like everyone else." I wondered what exactly he had in mind. Certainly not everyone has the same opportunities in life due to class, gender, race, sexual preference and numerous other inequities and complexities of time and situation. It seems as though these statements tacitly assume something… that equality is available to everyone BUT people with Down Syndrome.
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> Field note: August 23, 2006

Throughout my experiences with advocacy, I noticed a lack of commentary on other forms of social inequity or other socially constructed differences. Advocates bemoaned the low wages and impoverishment accrued through cognitive disability and the dearth of options for employment that were available to people with Down Syndrome, yet I never heard any effort to respond to the concerns around sustainable wages for all, or other similar structurally inflected social realities. This reluctance to align explicitly with social movements associated with the struggles of others, combined with a homogenized version of an ideal democracy where egalitarianism is the norm, effectively constructed living under the description of Down Syndrome as a special kind of excluded group, and one that was especially and perhaps even more deserving of a gateway to freedom, whatever that might mean. Over time, I wondered if this was an effect of the specific focus required of advocacy, combined with the social status of advocates, many of whom appeared likely to have experienced economic, racial and other privileges. This, for me, queried the boundaries of who the *us* actually were.

With equal measure, *just like us* sentiments reflected on individuals, and individual aspects of personality or life course. Conversation at my table during the World Advocacy Day workshop visited commonplace representations, even within advocacy, of the singular personality described for people with Down Syndrome. Often, the personality of the person with Down Syndrome is described to be social, affectionate, emotionally insightful, warm, and prone to hug giving. As part of this discussion, one mother exclaimed that her daughter had "quite a temper," refuting the typification. She told a story of her daughter being stared at by someone at a store. After a few moments of discomfort, the daughter marched toward the starer and said in a loud tone (mimicked by the mother telling the story as a gruff, commanding, and lowered voice), "What are you looking at?" This mother was adamant to express her observation that children with Down Syndrome were extremely different from one another. She mentioned it three times throughout the morning workshop discussions. Having a temper, and a unique set of personality characteristics made her daughter *just like us* and less like a predictable pattern of bundled behavior.

Commentary about social reactions, especially in the form of stares, was common. One interviewee told about being accosted by a stranger while shopping in a mall with friends. Her son, who has Down Syndrome, was playing with their friend's toddler when a stranger approached the parent, claiming, "you've got to get your son away from that baby!" The interviewee added, "You know I'd like stuff like that to change where he doesn't get looked at funny and stuff like that, because he is not different you know. He's like anybody else."

In a conversation between doctors, one told a story about a young man who he has seen as a patient for about fifteen years and who is now in his mid-thirties. Despite the fact that the storyteller is a pediatrician, he continued to see this patient because, "you know, there's no one else," referring to the fact that people often have a difficult time finding doctors who are knowledgeable about adults with Down Syndrome. Everyone around the room nodded. One day, the man called the doctor, saying that he needed to talk about his life. The doctor suggested that he make an appointment and he did, arriving with a family member. During the appointment, the patient said that he was unhappy. It wasn't that he didn't like his job. He did, but he was unsatisfied with how things were going. He "wanted more vacations," and "wanted more money," and "wanted more fun." The doctor reflected on the fact that this man was cognitively "high functioning," and he "knew enough" to want more, but also knew simultaneously that he was limited and probably wasn't going to get any more from his work life at a local grocery store. The doctor telling the story laughed and said that he responded to this man by saying that he wanted more money, more vacation, and more fun too! Everyone around the table laughed with him. This doctor was saying, this man is *just like us*.

Another doctor in the conversation challenged the first, claiming that this man's situation was significantly different from the doctor's in that the doctor could plan and re-group, but that the man with Down Syndrome had to face limits in a different way. He did not have the possibilities that the doctor had and he was also dependant upon what others offered him – that his employers were kind and understanding of people with cognitive disabilities for example, or the other services that organizations and individuals

offer. This is different, the challenger seemed to be saying. This man's life is different than yours.

The first doctor resisted this claim, and talked about the limits that all of us must face at one time or another. He commented that despite the man's initiation of the conversation with his doctor, once his need for talk became public, "all sorts of people" wanted him medicated and suggested that doctor prescribe anti-depressants. Instead, the doctor made some suggestions to the young man for dealing with his dismay. In the end, the doctor asserted, the man resolved this life issue for himself and seems to be doing fine. This story prompted another field note entry regarding structural economic divisions in society:

> This man's dilemma doesn't sound much different than anyone else who has felt stuck in a dead-end job and an overall situation that cannot be changed. I remember once feeling the same way. It is that dismay that shows up when you have no reason to believe that a situation will ever change. The pay won't change, the amount of vacation won't change, the status level won't change. And that is quite a dilemma. Here, at this table, upper class elites concern themselves with the dilemmas of a man who has Down Syndrome and has obvious limits (to them) as to what he can do and accomplish. Yet millions of other people without a designated condition like Down Syndrome are, in fact, in the same plight. For whatever reason, they are occupying lesser status positions that are never going to pay much more than they are paid now. No change in sight. The diagnosis of a cognitive impairment motivates elites to think on their behalf. But for those without such a designation, it is understood to be within their purview to make changes, even though structural forces are often stronger than individual will. I guess that folks are only partially concerned with social justice. Just so long as their constituents are impacted. For doctors of people with Down Syndrome, these patients become "their people" and their concerns become the doctors' concerns.
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> Field note: December 3, 2006

Lastly, parenting is often described within the boundaries of typical expectations of the life course. When my husband Don and I attended a fundraiser for a Down Syndrome organization, a child with Down Syndrome – a boy – came bounding up to Don and gave

him a big hug, nearly spilling Don's wine. His mother came up behind him. The boy greeted us with a big hello and we greeted him back. The mom, speaking gently, reminded him that it wasn't a good idea to hug people that you didn't know right off the bat, and demonstrated shaking hands. We all shook hands, and he was introduced to us. His name was Dylan. "My name is Betsy," I said as I held out my hand. He shook it solemnly. His mom laughed and said, "We're trying to teach him how to *be* with people." I asked her how old Dylan was, and she said, "Eleven." I was surprised, as I would have placed him by size and appearance at about eight years old. She said, "well, almost twelve, we're hitting those pre-teen years." She made a fake grimace, as if to say, 'you know about teenage years.' I laughed and said, "Watch out!" and she laughed too. What struck me about this interchange was that it was in the realm of the customary for any parent facing "those teenage years" in American society. She was simply saying what many parents say about their kids ages when they are at that age, and yet certainly "teenage years" for Dylan, who was learning not to hug so much, might be a different ball game altogether. That was the end of our conversation. Dylan bounced away and his mom followed slowly behind him, tracing his every step.

Genetics and Not-Disease

One question I regularly asked those involved in advocacy for individuals with Down Syndrome was a simple one: What is Down Syndrome? The answer was far from simple. While all respondents referenced a genetic explanation first, indicating their orientation to biomedicine by recounting the situation of genetic trisomy as the cause of Down Syndrome, most elaborated much further and very poetically beyond that, touching

on philosophy and theology. Down Syndrome emerged as a situation of trisomy, but also as a way of life, a style of being, a cultural group that included those without Down Syndrome, and an entity that encompassed entire families and not just individuals. Down Syndrome, as a concept, marked lessons learned by parents, siblings, and other advocates. Down Syndrome was also about being kind in the world, and appreciating all that was, and it carried with it an uber-humane quality. Down Syndrome drew people together and strengthened their awareness of a far-too-fragile world. Down Syndrome, as communicated to me through advocacy conferences and interviews, referred to that which had slipped away from the grasp and gaze of the medical. In this potent way, Down Syndrome was not a disease and thus the statement "a vision of a world without Down Syndrome" could not be thought at the level of advocacy politics.

In the shifting scene of genetical science and its collaboration with medicine, where attention now centers on vulnerabilities and susceptibilities rather than actual disease states (Rose 2003a and 2003b), this use of genetics as an advocacy discourse becomes possible. Its power is that it can establish difference and distinction without relying heavily on tropes of disease. Instead, the medical conditions that an extra chromosome make possible but not-yet-determined can be conceptualized as diseases for which attention should be paid, marking the territory and limits of the ethical. Down Syndrome is enacted through this discourse as a static situation of a fixed amount of extra [chromosomal material], and allowed the room to roam freely in symbolic play. Despite the fact that Down Syndrome is the primary situation diagnosed through amniocentesis and, therefore, considered pathological through biomedical and governmental lenses,

once born the advocacy associated with living under the description of Down Syndrome refute the claim to disease and discern meaning along differing trajectories of thought.

Neurodiversity begins to come into view, here, as a fully embodied expression of difference along the continuum of human variation, a situation that relies as much upon difference as it does on similarity. Genetical discourse makes the space for this new social formation to surface, deferring moral culpability away from the individual, or the parents, and outwards toward the larger society that often enough insists on viewing Down Syndrome through a pathological lens. In this register, Down Syndrome itself becomes the seat of the soul and medical attention is only required for its proliferating effects. In this respect, science and medicine *transform* the life chances of an individual with Down Syndrome, often enabling a longer and healthier life, as well as enacting a new and different Down Syndrome from that which has gone before in other cohorts and generations. It could be argued that here we see biomedicalization at work, transforming the experience of living under the description of Down Syndrome in a deeply embodied way. However, biomedicalization-as-transformation is only half of the story.

During my fieldwork, an event happened that revealed the stakes the effects of the historical debates concerning human status have on the activities of advocates working on behalf of people with Down Syndrome. This event reverberated through groups associated with advocacy, and advocates perceived it as an event of painful significance. It centered upon a statement of new recommendations for prenatal testing protocols that was made by the American College of Obstetricians and Gynecologists (ACOG).

ACOG: PRENATAL TESTING

The situation of Down Syndrome is culturally complex. While medical interventions have made extended longevity and a physiologically easier life possible, evaluative technologies associated with prenatal care also result in an absence of life with Down Syndrome. In January 2007, and in the middle of my fieldwork, the American College of Obstetricians and Gynecologists (ACOG) issued new recommendations for prenatal testing associated with "chromosomal abnormalities," including Down Syndrome (American College of Obstetricians and Gynecologists 2007). The crux of the new recommendations was the expansion of screening for the risk that a fetus had chromosomal anomalies associated with Down Syndrome and other trisomic conditions. Previously, pregnant women over the age of 35 were offered screening and diagnostic technologies. Arguing that this age limit was an arbitrary distinction, ACOG's new recommendations were to offer the screening and diagnostic technologies to all pregnant women. With the advent of multiple screening technologies that can be utilized in the first trimester of pregnancy, ACOG argued that screening for risk of a fetus or pre-born baby with Down Syndrome should be offered to everyone. Should the initial screening reveal a risk for this chromosomal anomaly, then the more familiar invasive diagnostic testing of amniocentesis would be offered to confirm whether or not Down Syndrome trisomy was actual.

This statement set off a flurry of media activity by advocacy groups and individuals centered on the association between prenatal testing and pregnancy termination, what George Will, in his editorial on the topic, called a "search-and-destroy mission" (Will 2007). At the NDSC annual meeting in Kansas City that year, countless

speakers made critical reference to the new recommendations and a plenary speaker, journalist and advocate Patricia Bauer, devoted her entire talk to the subject of the recommendations, cultural attitudes and resistances to those with Down Syndrome. Additionally, a special workshop session was called to brainstorm further responses.

NDSC Workshop: Fury and Sound

On the final day of the National Down Syndrome Congress in Kansas City in August 2007, I attended a workshop designed to discuss and craft a response to the still-new recommendations of the American College of Obsetricians and Gynecologists. The meeting was held in a small breakout conference room, and quickly the attendees filled the room. The passions of parents in this meeting were very palpable. The room was full of talk and interruption as people tripped over one another to state their opinion, or talk about their own experience with prenatal testing. One man recounted how he and his wife pursued amniocentesis with no intention to terminate the pregnancy if they received a diagnosis of Down Syndrome. Instead, they wanted information. However, he claimed that the consultation with the genetic counselor completely broke down when this was revealed. The counselor saw only the need to encourage termination of the pregnancy. Around the room people nodded, as if to assert that this predisposition of genetic counselors was known to them all.

Seated next to me was a woman who began a conversation with me almost from the moment she sat down. Prior to the workshop's beginning, she settled in to telling me about herself, and her relationship to the ACOG recommendations and issues of abortion in general. As the meeting began and progressed, she interspersed whispers into my ear in

a near constant discourse on the event's proceedings, agreeing here, adding her own insights there, and generally talking unceasingly. As her story unwound, I became deeply aware of two things: 1) I was listening to an ardent foe of the use of abortion for any reason, and 2) she seemed to assume that I agreed with her. I felt pressed into a stance of a silent witness, and felt nervous that my cover as someone with ambivalent feelings on all sides of the question of abortion would be blown. In a word, I felt socially trapped.

As a longtime feminist, I have been of the opinion that abortion should be legal and accessible to all women, and yet I have been cognizant that I would find enacting the choice of abortion very difficult. Throughout my fieldwork, in interviews and at conferences, I was aware that I was interacting with many who had strong anti-abortion positions, at least in the situation of a fetal or pre-birth diagnosis of Down Syndrome. And yet despite my familiarity with the passions and pathos of the Down Syndrome community concerning the issue of prenatal diagnosis, I felt anxious and fearful of my ambivalence in this workshop setting. This complex set of feelings seemed grounded in the intensity of the moment, and the fervor of those sitting near to me. This was new emotional territory for me, and my discomfort surprised me.

The workshop was a participatory and generative one, and so we inevitably broke out into smaller group discussions. My neighbor joined me in a discussion concerning policy. Her story, quietly percolating in my left ear for twenty minutes burst into full form in the discussion, which she steered in her dedicated fashion to the issue of abortion and its problems. We were two of three women in a small group where the other four or five participants were men. With the exception of myself, all the other participants were

parents of people with Down Syndrome, having lived under the description of Down Syndrome for many years, if not in some cases decades.

Generally speaking, she enjoyed support from other participants in the small discussion group, with smiles and nods all around. This was one of those moments where I needed to find a way to listen, despite any disagreement or reactions I might have. The process of listening, while not swaying my personal politics, was transformative nonetheless. Seldom had I been placed in such an extreme position of ideological opposition with the express purpose to listen and understand. Situated in a conference in midwestern United States city, surrounded by middle class European-Americans that very much resembled my own "look," I was seated in the heart of difference and confronting my own fears of needing and wanting to be appreciated, not only on a personal level but in the name of anthropological rapport in the field.

As I sat there, feeling frozen in place and unsure of my next steps, someone I knew to be involved in the NDSC in a professional capacity dropped in to listen to how our discussion was unfolding. She sat down and listened for a few minutes before announcing, with a certainty that seemed to catch everyone's attention, "I told myself that I would remain quiet for this discussion, but I have to say something. Regardless of what opinions you may have – and you are free to be whoever you are about abortion – the NDSC is *not* going to jump into the abortion debate. I want to make that perfectly clear. This is *not* something we want to do. You just do not want to go there. The NDSC is not going to go there" (this was paraphrased and from my notes written shortly after the discussion). Everyone in the discussion stopped to look at her. No one challenged her,

and the conversation moved away to other topics of policy, although after she left our group and moved on to another my neighbor's fiercely whispered opinions continued.

Not About Abortion

Despite this story, it would be a mistake to portray the advocacy movement for Down Syndrome as a movement cleaved to the anti-abortion movement. Instead, perhaps the reverse may be more applicable; a cursory search of the blogosphere suggests instead that the anti-abortion movement often draws moral power from practices of prenatal testing. However, as one longtime advocate commented to me, "we respect the laws of the land," when asked directly about prenatal testing anxieties. Later, he added, "I don't mean this in a religious kind of a way at all but there is a gift in a strange kind of a way that come to all of us […] and I wouldn't wish Down Syndrome on somebody but it's not the end of life or the end of the world for people either." A feminist advocate at a conference spoke of her flexible and situational ethical stance on the matter of prenatal diagnosis and the termination of pregnancy. Although she was politically "pro-choice," she simultaneously held the belief that a pregnancy should not be ended for the reason of a pre-natal diagnosis of Down Syndrome. Rayna Rapp has argued that parents – and particularly women – become *moral pioneers* in their encounter with the ethical through prenatal testing, by making decisions about the viability and desirability of certain forms of human life. These statements and political positions reflect the landscape of such moral pioneering.

Issues surrounding reproductive politics are difficult to parse, and my discomfort described previously in the workshop highlights my own tenuous and ambivalent

standpoint. And yet it must be understood that the reactions of parents is far more than simple resistance to the reach of medicine or the state into the body, or bodies as the case may be, to mandate or regulate the perfection of born babies, and foster the creation of non-disfigured bodies. Although the surface rhetoric emphasizes pregnancy termination for incorrect rationales, the emotional turmoil over these recommendations reveals other hungers.

At stake is the body of the community associated with advocacy for Down Syndrome. Denying this community the literal bodies of people with Down syndrome through recommendations that may provoke more pregnancy terminations is threatening to all this community stands for and its very existence. It is not simply services, or programs, or treatments that they desire. Advocates living under the description of Down Syndrome hunger for acceptance, value, respect, and a sense of place in the world that is thoroughly normalized. The feminist advocate I noted earlier, in an interview, commented on the community aspects of being a parent:

> I would never change it for the world that I had a child with Down Syndrome. I don't think I would know the people I have in my life now. I wouldn't be doing what I'm doing. It was to me kind of meant to be. So it's cool. I like it.

Later, when I asked her about the ACOG recommendations and her concerns, she spoke about the negative effects the ability to test and end pregnancies had on the existing children and adults with Down Syndrome. Following a story told about a family in Canada who were not allowed to sponsor the immigration of a family member from Brazil who had Down Syndrome, she added that "so to me that's what this kind of

philosophy of early testing [does.] So you can have a choice to abort really just sends such a negative message that trickles down." Ultimately, she concluded:

> I do think all parents with Down Syndrome, and I think even parents with kids with other disabilities, are really afraid of some of this early screening because they feel it's encouraging more families to abort kids that are, could be, perfectly viable individuals and do wonderful things in society!

Very recently, in the United Kingdom, research thought to move science one step towards producing a prenatal screen for autism was reported in the public media. The Director of the research team, Professor Simon Baren-Cohen, as well as other leading researchers, was reported to have issued a call for a bioethical debate on these potential practices. Dr. Baron-Cohen was reported to have said:

> If there was a prenatal test for autism, would this be desirable? What would we lose if children with autistic spectrum disorder were eliminated from the population? We should start debating this. There is a test for Down's syndrome and that is legal and parents exercise their right to choose termination, but autism is often linked with talent. It is a different kind of condition.
>
> Dr. Baron-Cohen, reported in the Daily Telegraph, Wardrop 2009

Dr. Baron-Cohen's call to ethics, and his comparison to existing prenatal testing in Down Syndrome, reveal the contours of what the stakes actually are for those living under the description of Down Syndrome. Down Syndrome is seen first and foremost as a situation of lack (cognitive disability), incompetence, and as a non-contribution, if not burden, to general society. Skills of a particular type in the situation of autism are accorded value and respect, despite the apparent differences also noted with its spectrum. As a result, issues related to autism are awarded the promise of a more extended ethical attention.

For the advocacy community associated with Down Syndrome, the absence of the bodies that made it possible is an unthinkable loss. The slow absence cultivated through

increased incidence of pregnancy termination would change the landscape of the community and of living under the description of Down Syndrome. In order to continue to push for the cultural change they desire, they need the bodies and the numbers to increase, not decrease. Although few parents would readily admit to wishing that other potential parents would experience the parenting of a child with Down Syndrome, the pragmatic fact is that the more babies there are, the more parents there are, the more potential for population growth of their community.

In a health advocacy market where bodies make a difference, marginality is seen in terms of numbers, and there is a compelling force to push the numbers higher. We see this with Alzheimer's Disease through the steady increase in the numbers that the Alzheimer's association can claim as "their own," people with a diagnosis of the disease. More people, more bodies, and more numbers increase the potential for more attention. This is as true for Down Syndrome as it is for Alzheimer's Disease.

COGNITIVE DISABILITY UNDER ANOTHER DESCRIPTION

Cognitive difference, change, and decline when living under the description of Alzheimer's Disease and without Down Syndrome is an entirely different story. While various calls for an attention to personhood and human status are regularly made as part of the improvement discourses on care, the issue of making life possible is crafted along a differing axis. If there is human worth and value invoked through the rhetoric, it is because of a life previous to a diagnosis of Alzheimer's Disease is presumed to have contributed to society through work or other contributions. The constructed status of people living under the description of Alzheimer's Disease as human, refracted through

normalization and the social construction of a life course, is understood as a preexisting state of normal from which degeneration occurred. Recouping personhood, then, becomes a salvage project to find the human in the apparent decline and changing flux of pathology. It is a re-gathering in, instead of a presumption of failure and difference from the start.

Old age as a social construct, often infused with notions of a wisdom derived from experience in its ideal, is often seen as the culmination of a solidly human life. Yet, a life lived under the description of Alzheimer's Disease is often construed to be a human life becoming strange. The question that arises from this uncertain strangeness is where the human and person actually went. In the advocacy movement associated with Alzheimer's Disease, in contrast with the one associated with Down Syndrome, it is not a matter of asserting the value of the human person, but instead an effort is made to go looking for the person. Perhaps the person is hiding in the brain, in the past, in the carers, or in the story created of the human beforeness, the before-Alzheimer's Disease state. In the next chapter, I will consider the use of memory as the defining cultural and metaphoric feature of Alzheimer's Disease, exploring the political quality of this frame of medicalization.

CHAPTER FOUR: MAKING MEMORY

Alzheimer's Disease is the second most feared disease in America after Cancer.
The Alzheimer's Project, an HBO Documentary

I always tell people I haven't lost my mind; I'm not crazy.
I've only lost some brain cells.
Quoted in the Alzheimer's Association Report, Voices of Alzheimer's Disease

If you want to talk to people with Alzheimer's Disease, talk to the early stagers.
Advice from a colleague

In Chapter Three, I detailed the use of genetic explanations for Down Syndrome in advocacy settings in order to demonstrate what was at stake for advocates living under the description of Down Syndrome. This chapter investigates the uses to which memory is put in matters related to Alzheimer's Disease and highlights some of the stakes in advocacy surrounding Alzheimer's Disease. Alzheimer's Disease, figured as a disease of memory, produces meaning in the contemporary that often appears to terrify. The use of memory also mediates and softens other kinds of social terrors and stigmas associated with (in)competence.

In the advocacy scene of Down Syndrome, the materiality of trisomy and a genetics discourse serves advocacy by evoking concrete material reality and evidence of human diversity, a neurodiversity rhetoric. A way of talking that utilizes the molecular bits known as genes and proteins produces a sense of cause (the trisomy causes patterned anomalies) and a neutralized explanation for difference. In contrast, the memory discourse, made scientific, does not capture a similar seeming-neutral materiality. While the emphasis on the molecular remains present in discoursing about Alzheimer's Disease

as a disease of memory (genes, proteins, neuronal processes, neurons), memory and its losses retain an ephemeral and mysterious quality as it is stretched between the normal and the pathological, competence and incompetence.

Interestingly, among some clinicians and scientists, the report that people with Down Syndrome do not present with memory losses as primary symptoms of Alzheimer's Disease is somewhat common. Instead, clinicians comment that the primary symptoms of Alzheimer's Disease for individuals who have Down Syndrome are behavioral changes, and not memory changes. This perception prompted one skeptical clinician specialist in Down Syndrome (an interviewee) to retort, "Well, if it isn't memory, it isn't Alzheimer's Disease." Setting aside the controversy as to what the prevalence rate of Alzheimer's Disease actually might be among people with Down Syndrome, this chapter investigates the uses of memory as a discourse in advocacy for Alzheimer's Disease.

MEMORO-POLITICS

> The primary image for the conference, appearing on all advertising and scheduling materials, is a transparent human head, crisscrossed by lines in symmetrical and geometrical patterns, presumably signifying neuronal activity. The lines cross with more density and with thicker lines just above the ear and across the top of the head. They extend across the face (the portion that we can see, the image is in profile) and down the neck, to just above where shoulders would begin. The face profile has shadows around the eyes, under the nose, and around the mouth. This image of a hairless human head reads to me as male, although I imagine some might make an argument that it is neutral. The profile also includes something that looks like an 'adam's apple." The face, transparent to the criss-crossing lines, also appears light in color and the facial features themselves conform to many aspects of northern European ancestry. Lastly, if given a chronological human age, the individual thus represented might be placed in his thirties or forties. The stylized smoothness and firmness of the image suggest that this human is not-old at all. This image

> is on the main screen located centrally over the podium, with speaker and table for moderators.
>
> Field note, International Congress on Alzheimer's Disease, Madrid: July 17, 2006

Alzheimer's Disease is spoken about and understood primarily through a language of memory loss. It is the subjective sense of memory gaps that catalyzes individual and voluntary visits to "memory" (often, neurology) clinics all over the United States. And it is a family, friend, or other outsider observation of memory losses in an individual that encourages that visit. In the clinic, memory is tested and memory losses defined by the test suggest a diagnosis of Alzheimer's Disease. It is memory shifts and anomalous interactions that foster the fear-laden question, "Is it Alzheimer's?" In the context of Alzheimer's Disease, it is easy to take memory and its losses very much for granted as explanation of perceived deficits. Furthermore, memory is often presumed to be universal as a human capability across time.

Work by historians and philosophers emphasize that this is not so (see Yates 1966; Carruthers 1990; Warnock 1987). The import of this historical work is the observation that a seemingly universal aspect of the human condition – memory – is interpreted and practiced in very different ways and that the effects of these differences shapes both the formation of subjectivities and the collective production of knowledge. In modernity, memory has acquired its own dynamism, informed historically by a theological matrix associated with soul or spirit and also by efforts to pin it down through science.

Ian Hacking calls the scientific investigations into memory, and humanity, *memoro-politics*. He elaborates upon what he calls depth knowledge, a concept he claims

parallels Foucault's concept savoir, and defines the depth knowledge of the sciences of memory as the knowledge that "there are certain sorts of truths about memory and forgetting" (Hacking 1996:69). This idea, that science is or will be capable of uncovering the facts about memory, drives the sciences of memory and the politics that emerge from them.

Hacking argues that the emergence of the sciences of memory is grounded in attempts to study the soul and claim knowledge about that which previously had been resistant to science. Hacking claims that the conscious intentions of early investigators were for these sciences to become "surrogates for the soul," resulting in its secularization. This explains its particular cachet in political battles, for "spiritual battles are fought not on the explicit ground of the soul, but on the terrain of memory, where we suppose that there is such a thing to be had" (Hacking 1995:5). Memory, as an object of science, is apparently more potent than explicit moral and ethical claims.

Memoro-politics is Hacking's term to refer to a realm of power mediated by the expert knowledge of the sciences of memory. Hacking argues that the underlying depth knowledge of these sciences facilitates a politics of both memory and forgetting that are "power struggle[s] built around knowledge, or claims to knowledge" about memory (Hacking 1996:69). He adds memoro-politics to Foucault's conceptualization of anatomo-politics and bio-politics, disciplinary orientations to the human body and regulatory controls of the population, respectively. Foucault claims that these two poles are emergent technologies associated with modernity (Foucault 1978). Hacking argues for the addition of memoro-politics, cheekily turning Foucault's polar metaphor into a

tripod and asserts that this addition is necessary to address the power struggles founded upon the knowledge production surrounding the human soul.

Memoro-politics is an apt descriptor of the power-laden and largely secularized realm in which scientists, clinicians, and advocates associated with Alzheimer's Disease work to enable the invention of a cure for it. In this world, soul is parsed into molecularized bits – genes, proteins, transmitters – engaged in a pathological process leading inexorably to soul's degeneration and death, beginning with so-called normal aging. It is no wonder that the terrain of Alzheimer Disease is often terror-laden for many. One could speculate that in reaction to this progressive secularization and diminutization, the largesse of soul is revitalized through concepts of person and self. Looking back to Chapter Three, where I explored the shifting and tenuous purchase that Down Syndrome has on the concept of human, it is apparent why memory as an extension of human and soul could be denied those with Down Syndrome in the discourse on Alzheimer's Disease. Viewed first through a calibration of cognitive difference, people living under the description of Down Syndrome are first evaluated for their behaviors, and not their memories, which, it is often presumed, they do not have in great number.

One can think of the aging body in American society as a potent site of memory, or "lieux de mémoire," with Alzheimer's Disease, a disease of memory and its losses, as it's most focused problematization (Nora 1989). Discourse about aging, memory fluctuations, and Alzheimer's Disease enacts a public conversation devoted to remembering memory and reviving the narrative of the modern: that movement and progress entail losses and decline that are barely remembered. Conceptualizing these memory losses as disease

draws a defining circle around memory's losses, rendering that which falls within the disease construct closed and concentrated. And yet the metaphor of memory simultaneously allows for a range of meaning, taking into account both the secular and the spiritual, life and death, cycles and returns, all of which become a part of the subjective experience and memoro-politics associated with living under the description of Alzheimer's Disease. This will be explored ethnographically in this chapter, and in Chapter Six.

In Chapter Three, I explored the elaborations of the human/animal divide as it was applied to people with Down Syndrome. This historical echo, and the contemporary reality of ongoing marginalization, cultivates the stakes advocates living under the description of Down Syndrome have for a continually making human project. In making human, a scientific genetics discourse is drawn upon to introduce neutrality and eschew metaphors of pathology and disease. This same discourse, we will see in Chapter Five, haunts potential (re)turns towards a disease model for Down Syndrome advocacy. Both efforts in the making human project are encounters with the ethical.

In the world of Alzheimer Disease, a human/non-human divide is made apparent through the discourse on memory and its losses. Memory, as a stand-in for soul and self, contributes to the fear and terror associated with living under the description of Alzheimer's Disease. As will be suggested in this chapter, memory loss is also utilized to mask other concerns about competence and function, detaching Alzheimer's Disease from stigmatized behaviors.

MEMORY IN THE CLINIC

> When Dr. Smith returned from the waiting room, she brought three women with her. One was the patient and two were her supporters, a sister and a friend. The patient, Louise, was taller than the other two and heavyset. She was wearing black or dark blue corduroys, sensible and comfortable shoes, and a sweatshirt type of top. Her hair was dark but silvering slightly in large curls on her head, cut short. She wore a tiny bit of make-up and glasses. She sat down in the chair just to the right of the desk for Dr. Smith. Dr. Smith's desk was small, holding a computer monitor and little else. She did not use the computer during the interview, and there was a small space on the top of the desk for her file, lying flat so that she could take notes. There was a desk shelf/cupboard over the desk.
>
> Paul (another observer) and I sat on the examination bed, crinkling the paper put there to keep the surface under the hypothetical patient sanitary. To our right was a sink and counter, with wooden cupboard above and below. To Paul's left was a chair against the wall and between the examining bed and Dr. Smith. To my right, and at the end of the sink counter, was another chair, also against the wall and just inside the door. It was a tight fit for the six of us and, with the door closed for the patient history interview, a little stuffy.
>
> Field note: August 6, 2006

A portion of my fieldwork included participant observation in a neurology clinic that specialized in diagnosing various dementias. I observed patient interviews, neuropsychological testing, and interdisciplinary team meetings where potential diagnoses were discussed. I also attended the clinic-wide patient and research review meetings that were held on a weekly basis. In addition to assessing patients, this clinic also enrolled patients into various studies related to dementia, including Alzheimer's Disease.

Early in my fieldwork, I learned that this clinic choice was not one from which I could generalize to a global experience of assessment for Alzheimer's Disease. Emphasizing a (specialty) neurological approach, and located in an urban center, the doctors at this clinic often saw either patients whose symptoms were thought to be

difficult to diagnose (by the patient's primary doctor) or patients who were well-insured and inclined towards specialist assessment (they or their families had specifically requested the referral). Patients are assessed in many different types of settings in the United States, ranging from family practice and internist settings to geriatrician, neurological, and psychiatric settings. Different clinics emphasize separate pathways to assessment and diagnosis (Beard 2005), which position the patient differently. Additionally, access to specialists differs by geographic region, and urban or rural settings.

However, this clinic had a unique relationship to scientific research and participation in clinical trials. This enabled me to observe the movement of science through the clinic as well as discern the evolving understanding of Alzheimer's Disease symptoms and illness trajectory. Notably, the understanding of Alzheimer's Disease symptoms and pathology is reaching earlier and earlier into the life course, resulting in diagnosis that occurs at earlier ages and stages of disease than have been thought typical for the past thirty years. Alzheimer's Disease is moving from old age to all age as the production of knowledge proceeds, inventing new disease categories as it moves.

Emphasizing Memory

During my fieldwork period, the simple tripartite brochure for my clinic site emphasized clinical attention to memory in their mission, which is "to help persons with memory loss and their families." Although the brochure notes that not all memory loss is Alzheimer's Disease, and that there are other neurological diseases associated with memory losses, Alzheimer's Disease is the only condition that is actually defined:

> WHAT IS ALZHEIMER'S DISEASE?
> Alzheimer's disease is a specific neurological illness which affects over four million Americans. It is caused by the degeneration of brain cells. It usually begins with memory loss, word finding problems, and problems with navigation. As it progresses, there is further loss of memory, reasoning, and the ability to care for one's self.

The brochure also poses the question that frequents much of the educational literature on Alzheimer's Disease: "Is it Age? Or is it Alzheimer's?" This reflects the ongoing quandary of the clinic and of research into the realms of memory loss and disease, the distinction between what is often called "normal aging" and related cognitive changes, and the pathological progression known as Alzheimer's Disease. Drawing the line between the two has seldom been easy, and as we will see, is currently on the move.

The emphasis on memory loss as part of the clinic mission, coupled with a description of Alzheimer's Disease, a condition consistently associated with memory losses, belies the fact that there are many neurodegenerative disorders that comprise this clinic's specialty area. Given this, one is compelled to ask what the advantages to foregrounding memory in this instance might be. Does it make the potential for diagnostic assessment seem less frightening, or somehow more benign? Does it minimize "troublesome behaviors," or trouble in general? Does memory assist in striking a neutral tone about matters apparently related to a capacity of mind? Does memory as a concept contribute to a medicalization that removes moral overtones, and replaces these concerns with a disease concept?

As I witnessed neuropsychological testing, these questions began to dance, teasing out what was at stake in the use of a memory discourse, and how might that relate

to what Edgerton once called the "cloak of competence" necessary in United States society for general enfranchisement into the human condition (Edgerton 1993)

Witnessing Testing

It is probably an understatement to note that if one is facing neuropsychological testing, there is already some sense of trouble. These are not routine types of testing, nor are they customarily done merely for baseline purposes (unless one is participating in research as a "normal" control subject), and so their perceived necessity indicates that something may be amiss. Most patients encounter these tests for the first time when they are already under duress. As a result, they describe such testing with a great deal of emotional fervor. Examples from two public forums where people with Alzheimer's Disease speak to their diagnosis experiences suggest that the event is often remembered as puzzling, traumatic, or otherwise humbling:

> Well, this woman […] absolutely destroyed me in the way that she – I'm sure she meant well, but she didn't do a very good job. I was completely wiped out from talking with her and having her talking to me. And she said, "Come over to my office, and we'll do some testing." So she brought out four, five, six, seven, eight, I don't know how many pages of tests. And I couldn't do all of them, and then I got worse and worse and worse because I was just feeling completely debilitated by this, the way they were handling it.
>
> Town Hall Forum, Oakland: July 28, 2007

> And my daughter and I are just sitting there and looking at each other. […] And it was like if I'd been standing up, I would have gone right through the floor. It was like I had no idea. I had no nothing. I know I'm a nurse. But I don't know anything about Alzheimer's, you know? […] So, I said, "Oh." And so he closes the folder. He walks out of the room, and he leaves me there with my daughter. By that time, I got my big mouth going, and I went – we – I literally had to run after him. He was going for his next patient. He was going for his next patient. I ran after him, and I said, "Wait a minute. This is my body. This is me. You're going to treat, and

> you're going to tell me who do I go to for a second opinion? I want another opinion now."
>
> Town Hall Forum, Oakland: July 28, 2007

> The test was four hours, and I felt absolutely invaded. I felt so worthless. I felt so hopeless. I literally wanted to go home and get in the bed and cover up and not be talked to or heard or seen. It was a shameful thing. […] Now, I didn't show this. I just suffered. I sat there and suffered with one picture after the other through the test. I'm sure he's a very well known doctor, and I'm sure that he was doing a good job. My daughter thought so. But for me, it was awful.
>
> Town Hall Forum, Chicago: August 26, 2007

Although there are many conditions that might include cognitive deficits, the spectre of Alzheimer's Disease haunts the evaluation, and the stakes can feel high, at least for me as an observer. Here are my field notes from one such observation:

> As I watched the test unfold, I realized that the testing environment really affected how I observed, at least how it felt on the inside. As I watched, I felt as though I was rooting for the patient the whole time. In addition to the feeling of being a cheerleader, I was also taking the test in my head. I found myself checking whether I could answer the questions, reviewing the numbers and memorization tasks in my head, testing myself as to whether I knew what he was expected to perform. I felt as though I was also trying to do this quickly. So, I was rooting for the patient being tested, but I was also taking the test and internally comparing my responses to his. In a way, I was also competing with him. When he paused, I resisted the urge to help him out, through some sort of mental manipulation. Alternately, I found myself thinking the answers "loudly" so that he might get them from me. He didn't. I wanted him to do well on this test. And I was a little nervous for him. I hadn't known him for more than five minutes, but I quickly identified him as someone under siege. The consequences of this testing is quite profound, and I discovered that I really wanted him to succeed in it. Was it the testing environment that produced this response? Or his person? Or just a trip I went on on my own? It's hard to say, but I noted the response. He was already an underdog because he was the subject of testing. And I wanted him to prove everyone wrong.
>
> Field note: July 10, 2007

This man tested poorly and received a low score, although was not diagnosed with Alzheimer's Disease due to multiple physical symptoms that suggested something else. In contrast, here are similar notes for a later observation, where the patient scored very well:

> I observed his neuropsych evaluation and noticed that I was feeling bored. I was not having the same sensations I had the time before, of taking the test in my head and cheering for the testee. Instead, I noticed that he seemed to be doing fine. I also noticed that the examiner was giving him a test with different words, that she later noted was the harder test. I thought he did well, especially on the backward digit span, which I think is tricky for many people. I couldn't imagine that he did poorly, although there is something about taking the exam that makes people feel as if they were doing poorly. He seemed to move through the test as if the test was proving his memory losses, and he interpreted every feeling of gap or un-memory as a major indication of symptoms. For the most part, I felt sleepy and found myself being distracted from the exam. I wasn't taking it in my head this time.
>
> Field note: July 14, 2007

In this second example, the patient received a near perfect score, indicating that he was having little difficulty with a number of different types of memory tasks. His sole misstep on testing was that he misspelled the word WORLD when he was asked to spell it backwards.

Patient History

This clinic emphasized patient history in their diagnostic process, with up to an hour spent gathering information from the patient and his or her supporters. It was recommended to patients that they come with close associates – spouse or partner, sibling, or friend – to assist with the evaluation, and most people did this. Additionally, the supporters were interviewed separately from the patient while the patient was undergoing neuropsychological testing.

During Louise's patient interview (Louise was noted at the beginning of this section), the collaborative conversation between Dr. Smith, Louise, her sister, and her friend was a deep reminiscence of events more than twenty years past. Here are my observations of the patient history:

> Louise was quiet during this part of the day, and often deferred to her sister and friend. Once, she elegantly deferred her own answer to the doctor's question by looking at both of them, as if she were holding court, asking, "well, what do you two think?" At times, Louise seemed to struggle with her words. Her sentences were halting and simple. Occasionally, the wrong word would be substituted for the one she was trying to find. Louise is 63 years old. She laughed often, sometimes in a way that seemed a little puzzling, but in general my sense of things was that her laughter had something to do with her nervousness. Early in the interview, her lower chin and lip appeared to be trembling, and I wondered if she was scared.
>
> Field note: August 6, 2006

Louise was asked how long she thought she had memory problems, and she surprised her supporters by stating that she thought it had been about eight years. This was longer than her sister and friend had supposed. She asserted throughout the day that her primary problem was a "memory problem," although her supporters' defined their concerns as behavior or personality changes. I wondered if, given Louise's confidant assertion of her memory problem, that having a "memory problem" bore less stigma for her than having a "behavior problem."

The narrative that developed over the course of the patient history shifted on several occasions to earlier and earlier time periods in Louise's life, beginning with five years prior when she suffered a two-year depression, treated with medication. Louise retired from a job that had become very stressful for her during this time period. After Louise's eight-year time frame surprised her supporters, the conversation moved to 14

years prior when Louise took care of an ailing mother-in-law who treated her badly. Her supporters said that she had found taking care of the details of her mother-in-law's care (paperwork, bills, administration) extremely stressful and she was disorganized throughout. Last, the conversation rested on Louise's husband, who had committed suicide nearly twenty years before the clinic visit. At each of these story-anchoring moments, tenuously linked to the cause of the visit to the clinic, the participants in this conversation re-visited their memories and their sadness. Occasionally, their eyes filled with tears as they recalled these events. In the extended patient interview, evaluation and diagnosis of a "memory problem" quickly became a collective enactment of memory itself, especially of memories that were potent because of their associated trauma.

Alzheimer Disease

Louise was not diagnosed with Alzheimer's Disease. In fact, I did not witness a diagnosis of Alzheimer's Disease during my extended visit to this clinic, although I did witness two diagnoses of "normal aging," and one diagnosis of "perfectly healthy" (the latter individual was in her thirties and too young for a "normal aging" diagnosis.) I heard about patients diagnosed with Alzheimer's Disease in the weekly review meetings, but the evaluation of patients that I happened to observe did not point to Alzheimer's Disease. Instead, this was a point of humor in the weekly meetings, and for this group of doctors known for their sensitive evaluation of Alzheimer's Disease. One doctor, in an interview, claimed:

> I think straightforward Alzheimer's Disease is straightforward […] but we don't see many straightforward cases in our clinic anymore. I think this week we're gonna see Alzheimer's Disease, and we were laughing our brains out this morning hearing it. It was like, oh seventy five year old

> with memory loss! […] And then another one, and another one. We started roaring, like god we might see Alzheimer's Disease this week you know. […] And obviously the community is doing a really good job of making that diagnosis because we're not inundated with straightforward Alzheimer's Disease. […] You know the general public has no idea how many different neurodegenerative cognitive neurodegenerative illnesses there are in the world, no idea.

Thus, for this specialty clinic known for its expertise in memory loss, "straightforward" Alzheimer's Disease, a disease of memory, was disappearing from view.

MILD COGNITIVE IMPAIRMENT

Instead, Mild Cognitive Impairment (MCI) was more apparent, an artifact of earlier staged and aged diagnosis as well as the larger numbers of people who show up in clinics concerned primarily about their memory status. As a somewhat controversial diagnostic category, MCI – especially of the amnestic type – is often thought of as a possible precursor to Alzheimer's Disease. With this in mind, it is possible for a doctor to claim that a patient "converted" from MCI to Alzheimer's Disease when their abilities change, reflected by standard neuropsychological testing and the reports of their family members. In the weekly patient review meetings I attended, the trajectory of moving from MCI to Alzheimer's Disease was regularly invoked. Here are some examples (from my notes of the doctor's commentaries of their patients):

> A woman in her 70's, self-referred. Her husband was vague in description of what her problems might be. Upon testing, she did very poorly in memory and in learning. The presenting doc's sense was that she had early Alzheimer's Disease. The diagnosis was "MCI now, but AD in a year."
>
> Field note: June 5, 2006

> She is 74 with Alzheimer Disease. She was MCI and is now AD, but deteriorating slowly. She is on Aricept and stable on that. She has been

> seen since 2000, and just converted to Alzheimer Disease last year. She is APOE 4,4. And has a hydrocephalous looking MRI. At one point there was discussion about putting a shunt in, and now we're glad that we didn't. She is doing okay.
>
> July 1, 2007

In the clinic, MCI can be used to defer a formal diagnosis of Alzheimer's Disease, as was revealed in an interview with a clinician:

> Clinician: I think there's a little bit of demonization of aging that's going on I think in our field and where we emphasize the deficits that accumulate with aging and I think there are areas where deficits are common like memory. You know I think a lot in terms of function. And so my kind of clinical definitions at the moment still require a change in function. Someone is no longer functioning independently. That's- that's where I sort of draw the line of what I call Alzheimer's Disease.
>
> BP: And before that it might be
>
> Clinician: We call it MCI or something like that. So yea, it's kind of like a refuge for all of us who don't like to label people unnecessarily.
>
> BP: MCI?
>
> Clinician: Yea. We know a lot of those people do have Alzheimer's already. It's a clinical category. But we know that a lot of them will function well for a long time. And so for me there's no rush into giving people a diagnosis of a fatal disease unless we can really do something about it or it has a lot of clinical significance.
>
> BP: Is that decision affected primarily by the fact that there's no good treatment for Alzheimer's Disease?
>
> Clinician: I think it is! I think that if we had a cure we'd be much more aggressive about making the diagnosis. But we I think we're cautious about diagnosing something without a great treatment.

This commentary reveals the encounter with the ethical that clinicians experience in delivering a diagnosis of Alzheimer's Disease. One might surmise that people who undergo the rigors of cognitive testing are interested in hearing a full opinion from their

clinician, and that the choice to label their concerns differently could be construed as a betrayal. There are many diseases that are fatal, but nonetheless the diagnosis is made. This rationale for why a diagnostic punch might be pulled is puzzling and inconsistent with other diagnostic processes. Arguably, if a diagnosis is stalled until the individual is no longer able to function, it might be equally plausible that the individual may not be able to understand the diagnosis at that juncture. In the absence of cure, this doctor is saying, caring means to withhold information (but still prescribe the medications that are available for Alzheimer's Disease but under the diagnostic rationale of MCI). This choice is a negotiation between negative stereotypes of aging, the fallibility of medicine and its uncertainties, and perceptions of what a diagnosis of Alzheimer's Disease might do to (and for) an individual. It can also be viewed as remarkably paternalistic.

However, after noting that there is no diagnosis in a clinic devoted to neurodegeneration and dementia for which there is a cure, another clinician spoke of a conversation she had with the husband of a patient who is declining due to a non-Alzheimer's Disease dementia. She recounted:

> Clinician: And her husband said to me recently, I was thinking about how you knew where this was going when we first met you and you never, you know you couldn't say it. He wasn't saying that you wouldn't say it, it was that it wasn't right to say it. It wasn't accusatory, his tone. He was right. It breaks my heart actually. It's so true – you couldn't say it.

This patient had received the diagnosis of Lewy Body Disease, a dementia, but because it was unfamiliar to them as a diagnostic category they had little sense of what that might mean over time. And in the doctor's retelling of the husband's comments, he seems to have been saying that it was good that they did not know how the disease might affect them. Alzheimer's Disease, in contrast, has sustained an immense amount of

publicity, largely due to the public efforts of the Alzheimer's Association. Saying "Alzheimer's Disease" as a diagnosis conjures an entire trajectory in the imaginations of many such that one has a good sense of what living under the description of Alzheimer's Disease might entail, socially and physiologically. Another clinician claimed in an interview, "people know about Alzheimer's and they know how awful it is and that it gets worse. I think Alzheimer's is one of the worst of the common things that you can be told when you come to our clinic." MCI as a preliminary and cautious diagnosis may be another way of "not saying it" and deferring the description of Alzheimer's Disease entirely. Knowing that a diagnosis of Alzheimer's Disease can lead to what Annette Leibing has called a "biosocial death," some clinicians may simply bypass the opportunity of playing the role of grim reaper (Leibing 2006)

Mild Cognitive Impairment connotes something much more benign than does Alzheimer's Disease, and points to more comfortable associations with aging and forgetfulness. Throughout my fieldwork period, casual friends and acquaintances told me of their grandparents or aunts and uncles who were "forgetful," but "had nothing like Alzheimer's Disease, just aging." This was mentioned without fear or apprehension, and with a certainty that what they were seeing was not a disease. Despite the ongoing efforts of medicine and science to identify stages of Alzheimer's Disease, including very early stages, Alzheimer's Disease remains deeply entrenched representationally with difficulties associated with extreme behavioral oddities. This suggests that while the primary trope for Alzheimer's Disease is memory, its terror lies in the development of incapacity or inability to function.

The use of MCI is obviously flexible, depending upon clinician perspective. Despite some efforts to shield patients from the diagnosis of a disease state considered incurable and fatal, patients respond in various ways to a diagnosis of MCI. Although this study did not address how patient's view such a diagnosis, there is evidence that they often construe a diagnosis of MCI to be a diagnosis of Alzheimer's Disease, and that their social strategies around identity are similar between the two conditions (Beard 2005, Beard and Fox 2008). This reflects what clinicians seem to believe: "we know a lot of these people do have Alzheimer's Disease already."

At a conference reception, a clinical psychologist recounted to me a common rationale for why MCI as a diagnostic category is valuable. He said that he saw "a lot of MCI," and that he thought it was good for people to receive and know their diagnosis. Commenting further, he said that it is good for them because it gives them control over how things will go with them and helps them to make plans. He noted that the diagnosis helps them talk with their families because (he laughed), ultimately the families are the ones who will be caring for them and in charge. He added that a lot of people, including clinicians and scientists, think that MCI is Alzheimer's Disease.

COMPETENCE

In Chapter Three, the stakes for Down Syndrome advocacy were revealed through the comparison made by Baron-Cohen about ethical considerations for prenatal testing of autism. People with Down Syndrome have not customarily been viewed as competent, functional, or normal. I explored the discourses of genetics and "just like us" similarities used by advocacy to counteract this viewpoint.

In the preceding section, I demonstrated through data from a clinic that assesses neurodegenerative disorders that memory is the primary currency in the evaluation for Alzheimer's Disease. All patients undergo neuropsychological testing, a series of memory tasks, thereby making memory the first concern for all potential diagnoses. MCI was explored for its potential as a mask, or cloak, for other concerns. It is plausible to conclude from these data that the problem at hand is not memory, but function or competence.

In 1965, Robert B. Edgerton wrote an ethnography on the topic of competence in United States society, catalyzing a minor literature. He studied recently de-institutionalized people diagnosed as "mildly mentally retarded" (Edgerton 1993). Informed by Erving Goffman's orientation toward asylums and stigma, he analyzed their efforts to maintain an image of competence in a world that labeled them incompetent. (Edgerton 1993; Goffman 1961, 1963). This study revealed the importance of appearing competent in the United States, and the stakes for those who struggle with maintaining the appearance. He called these efforts to mask difference a "cloak of competence," and noted that successfully managing competence often required a second person considered more normal by society (Edgerton 1993).

Sue Estroff corroborates these claims through her ethnography of community-dwelling people with psychiatric diagnoses in the United States and their efforts to "make it" outside of institutions. She notes:

> Our cultural emphasis on independence and individuality is curiously matched with an underlying emphasis on conformity. One pays for those behaviors and experiences that exceed codified and consensually understood limits with losses in such valued possessions as freedom, self-determination, and control of one's life.
>
> Estroff 1981:175

These studies yield insight for the contemporary evaluation of memory losses, and its related discernment of Alzheimer's Disease. The sentiments and observations noted in the clinic reveal the contours of the problem inherent Alzheimer's Disease. Memory is (potentially) a mask for functional debilities and loss of competence in a society that relies extensively on individual autonomy. This differs from the ethnography by Edgerton because his study emphasizes the individual's effort to cultivate the "cloak." In the instance of Alzheimer's Disease, the discourse of memory itself assists in cloaking, or at least mediating, the core issues of competence and function. Memoro-politics, and its associated secularization of memory, is content to reduce memory loss to neurons and neuro-transmitters, a matter of brain rather than mind. Memory loss, while concerning to many, is more palatable than incompetence, with its potential association with other populations known for their incompetence, and its severe consequences for citizenship. This enables the recipient of the diagnosis to be able to say, "I haven't lost my mind. I'm not crazy. I've just lost a few brain cells." Furthermore, this assists in understanding why it might be that people with Down Syndrome are not identified as people suffering from memory loss, as noted in the opening paragraphs to this chapter. Instead, they are interpreted first through behavior change, largely because they have been viewed in terms of competence from a very early age.

MEMORY IN ADVOCACY

The discourse of memory is equally potent as a cloaking device in advocacy, which relies and builds upon its use in the clinic. Advocacy for Alzheimer's Disease emerged and developed following the dramatic demographic explosion of potential constituents

when the diagnostic category was expanded to include most people with senile dementia. However, the association of Alzheimer's Disease with older age is perceived as an obstacle to garnering public attention and concern, due to general perceptions of old age in American society. The awareness of age perceptions as an obstacle was discussed in my conversations with Alzheimer's Association staff members:

> BP: Are there any special challenges in your work due to the nature of the disease itself?
>
> Interviewee: Yes, I think that the fact that it affects older people primarily, you know over age seventy-five. That's the mean age of onset is seventy-four, seventy-five. I think it's easier to sell a younger disease, diseases affecting younger people and children because some people will say what difference does it make? If you're eighty five years old you only had so much time left…that's pretty harsh!
>
> BP: Do you hear that a lot?
>
> Interviewee: I don't hear it a lot I think people think it. And might use their good judgment and not say it.

Another individual was more explicit in how people were perceived to react to old age:

> Interviewee: That year's strategic plan […] this whole question of increasing public awareness was a huge strategic goal. And you know it continues to be a huge strategic goal for all kinds of organizational and mission related issues. There was an analysis done that suggested we needed to get the brand awareness up. Using focus group methodology […] it was discerned I think rightly that the image of Alzheimer disease was unapproachable by the general public. Because it was old, it was hopeless, it was totally disabled and living in your own pee in a nursing home. It was unattractive in terms of the general public. […] It was discerned through focus groups that boomers in particular were a leading edge, boomers would be an incredibly important audience to attract.[…] And so that's when the marketing people took over.

During the 2007 Public Policy forum of the Alzheimer's Association, held annually in Washington DC, I became interested in the representation of Alzheimer's Disease that was increasingly using people with Alzheimer's Disease who were of younger ages and at earlier stages of the presumed disease trajectory. While walking between legislator visits, I asked an Alzheimer's Association staff person what the effects of earlier stages and ages of Alzheimer's Disease had on policy and politics. She commented that it made things easier, linking it to branding of the disease. She said (paraphrased from my notes): "Just like it is easy to have sympathy for a child with a major disease, so it is easier for people to have sympathy for a younger sufferer of Alzheimer's Disease." During the same conference, and in conversation with another staff member, I heard another response, "I think that it gives someone for people to identify with."

This problem in representation becomes easier to understand when viewed through the statements of a theorist on competence and incompetence: "Childhood and senility are thus states-of-being that are understood as 'normal'" either a transitory pre-condition of competence, or a loss of adult competence that is a regrettable part of the scheme of things" (Jenkins 1998). Patrick F. Devleiger, through his study of incompetence and its effects on young adults with developmental disabilities, concludes:

> The incompetence of contemporary people with mental retardation is made present and obvious in public spaces, and is regulated through an ethic of avoidance. That avoidance is transformed in a public conspiracy that ignores incompetence. In American culture, the term 'disability' refers to the evidence of ability. […] At any point, American culture reveals itself as committed to preserving self-reliance.
>
> Devlieger 1998

In the case of Alzheimer's Disease, a response to cultural discomfort around the aging body and functional decline are effectively avoided through the public discourse of

memory loss as the primary symptom of Alzheimer's Disease. The Alzheimer's Association, charting a marketing course to garner attention for a disease, participates in this avoidance and, in so doing, neglects to challenge the general cultural dismay over functional declines that may be correlated with age, and ageism in general. In actuality, avoidance may promote that dismay.

Importantly, the fact that something might be "cloaked" does not mean that it is completely hidden. Nor is the avoidance that Devlieger describes an act of full denial of incompetence in the situation of Alzheimer's Disease. Indeed, the primary problem of competence and function is often in plain sight, but enveloped in a language of memory to make a direct understanding of incompetence difficult. The two are often conflated. For example, during an interview a respondent from the Alzheimer's Association commented (about medications), "I don't want someone deciding whether my memory, how much my memory is worth to pay. […] Would you pay five dollars a day if you could tie your shoes for another six months? That's kind of what we're talking about, so it's scary to have legislators making those kinds of calls… or insurance providers." Notably, if memory loss were simply or only about the ability to tie one's shoes, there would be ways to work around that difficulty and perhaps not as many people would be so frightened at losing it.

In 2009, HBO Documentary Films broadcast a four part series devoted to Alzheimer's Disease, entitled *The Alzheimer's Project*. This project was crafted to encompass many aspects of Alzheimer's Disease, including the research in science, the experience of caregivers, and the experience of families (including children). In one of the four videos, *The Memory Loss Tapes*, a potent example of the cloaking aspects of the

memory discourse is rendered. This four part series was produced in collaboration with the National Institutes of Health and the National Institute on Aging, and with assistance from the Alzheimer's Association, the Fidelity Charitable Gift Fund, and the Geoffrey Beene Gives Back Alzheimer's Initiative. It is available for streaming (Cookson and Doob 2009).

In *The Memory Loss Tapes,* six individuals who have been diagnosed with Alzheimer's disease are featured, three women and three men. Their stories are chronicled in disease progression order, meaning that the least impaired person's life is represented first and the most impaired last, highlighting the trajectory of decline associated with Alzheimer's Disease. The final vignette includes a documentation of the individual's death in a hospice center. Each vignette includes conversations with those who care for the individual with Alzheimer's Disease - daughters, sons, and spouses. It also includes footage of their residences – with families, in an assisted living residence (one story), and in a nursing home (one story).

These vignettes are replete with conversations and images of problems with competence, however they are "cloaked" and saturated with memory, beginning with the video's title. *The Memory Loss Tapes,* as title, points to memory loss as the defining feature of Alzheimer's Disease, as well as a technical orientation suggesting that memory can be rewound and replayed. This idea was in evidence throughout the video, for reminiscence on past accomplishments and skills was very strong.

Competence concerns in the video included (in the order of the features), forgetting names (but still being able to drive and participate in community activities), not being able to drive (the video documents the driving test and failure), difficulty navigating an

online blog by a person who worked at the top level of computer design and invention, repetitive questioning and confusion regarding one's activities (and living in an assisted living residence), mistaking one's image in the mirror for another person and denying that one knows one's son (and living in a nursing home), babbling or wandering (and requiring a fence around the perimeter of the house for safety), and being completely bedridden and dependent. The trajectory depicted was primarily one of competence and function, coupled with the efforts made by families and others to care for those they love through these obvious challenges. The video began with an epigraph attributed to Aeschuylus, 430 BC: "Memory is the mother of all wisdom," followed by an individual undergoing neuropsychological testing, where she was asked to provide the date, the season, the name of her small dog, and the president who preceded George W. Bush.

However, the movement towards total decline was depicted in an envelope of memory. The strongest use of memory was with the last participant, who had entertained children in his region of the country for decades as the lead in a children's television show. Throughout the vignette, the viewer witnesses the individual with Alzheimer's Disease watching his own 1950's, 1960's, and 1970's era television shows, which were also played for the viewer. For those viewers who were from that region of the country, I imagine that these images were familiar and evoked warm reminiscence of childhood afternoon TV. They remind the viewer that this man was an important part of their memories and their lives. The use of memory punctuates the fact that the individual with Alzheimer's Disease who was watching them is at his life's end, the images performing a kind of life review in the absence of his ability to do so. This resonates with the clinic

example of Louise, for whom being tested for memory loss evoked a collective memory of her life's traumas.

The memory discourse cloaks incompetence and function dilemmas because, as was seen in Chapter Three, incompetence can and has contributed to an attribution of non-human status. Unable to culturally accommodate both incompetence and human status easily, remembering and memory is drawn upon to re-shape and re-invigorate the soul in the face of decline. This is a different sort of memory from the reductions to neurons and neurotransmitters made by science, and a memory that defies secularization. Yet, it is one of the many animations of memory possible within modernity, and a discursive possibility within a disease metaphorically linked to memory's mysteries.

FROM PERSON-CENTERED CARE TO EARLY STAGE REPRESENTATION

Despite the sleight of hand diagnostic practice of Mild Cognitive Impairment noted earlier in the chapter, many people younger than age 65 are diagnosed with Alzheimer's Disease. The Alzheimer's Association estimates that there are 5.3 million people with a diagnosis of Alzheimer's Disease in the United States, of which 200,000 are under the age of 65 (Alzheimer's Association 2010). A high proportion of these individuals are not predisposed to Alzheimer's Disease of the genetically familial type. Explanations for the increase in Alzheimer's Disease diagnosis at higher levels for earlier ages rest on the technologies of assessment, which many claim are able to diagnose Alzheimer's Disease earlier in its course, and the demography of the baby boomer generation, which creates a larger population in these age ranges. It may also be linked to the daily publicity of the disease itself, and its effect of catalyzing concern and voluntary assessment for perceived

memory problems. This demographic, too, was recognized in my clinic site. In one patient review meeting I observed, and after a particularly long list of patients younger than the age of 70, one of the doctors present commented (paraphrased from my notes), "after hearing about all these 50-something people in the clinic, I'm pretty grateful to be around!" There were many nods of agreement to this sentiment.

This boom in Alzheimer's Disease diagnosis led to a plethora of articles in the public media centered on the theme "too young for Alzheimer's Disease." Googling this expression yields thousands of internet hits, many of which use a nearly identical phrasing. Public media often details the unique problems that people face when experiencing cognitive and functional decline at an earlier than expected age. Many articles note that people thus diagnosed have children who are teenagers or in college, have trouble keeping their jobs because of their debilities, or have health insurances accessed through their work. Unlike their older counterparts, they are not eligible in some cases to draw social security funds, or access Medicare. Bureaucratically, governance is not yet ready for them to be afflicted with an old age disease. Oddly, a disease which marks its beginnings in a 52 year old woman and then considered a dementia associated with the young has been reshaped as an iconic image of old age. However now, when 52-somethings report memory losses that are then diagnosed as Alzheimer Disease, they are considered "too young."

Many of these reports reiterate terror associated with the diagnosis, using the words of the person with the diagnosis as well as commentary by clinicians. One example is from ABC News. The article by Matt Davis features one woman, Lisa Carbo, who was diagnosed with Alzheimer's Disease at the age of 53. Describing her losses due to the

diagnosis, she includes the loss of her job, her boyfriend, and all her retirement plans. Watching her mother, at age 77, grow ill with Alzheimer's Disease she says, "It's like looking in a mirror and being terrified." Two doctors are cited who add commentary to the experience of early age diagnosis. Gary Small from UCLA claims:

> They see what's happened to others with this diagnosis. There's a sense of dread. It's like getting cancer, but in some ways it's worse. You're robbing people of their minds, what defines their humanity. I think it's a terrifying prospect for most people.

Dr. Murali Doraiswamy, professor from Duke, concurs, "For them, it can be very devastating. It can be almost like telling them, I don't want to say death sentence, but many of them take it very severely" (Davis 2009)

These newer representations of Alzheimer's Disease rely upon a memory discourse, because in the moment of the representation, incompetence is less apparent. Unlike earlier and historical images of Alzheimer's Disease, such as an abject Auguste Deter, these new voices engage with their diagnosis and their world. Terror is enacted by their look to their perceived future, and imagined end. This is not a diagnosis that entertains the idea that one might die of something else, even though many now live 8-12 years under the description of Alzheimer's Disease. This representation utilizing younger voices foregrounds memory, invokes terror, and avoids incompetence by filling the space with feeling and anxious anticipation.

This phenomenon has also cultivated new opportunities for representing Alzheimer's Disease. Renee Beard has chronicled the practical and ideological dilemmas associated with including those with Alzheimer's Disease into advocacy (Beard 2004). Among them are issues of representation. The Alzheimer's Association has relied on images of devastation and terror to garner interest in Alzheimer's Disease. The

appearance of individuals who appear, in their presentation, as relatively unharmed by the disease potentially challenges the conventional wisdom about Alzheimer's Disease (Beard 2004). However, the increase in the demographics of early stage, and earlier age disease has put pressure on the movement to take into account these new voices. Indeed, the demand for inclusion has created a pressure such that public apologies are made when these voices are not publicly present at advocacy related events.

In 2006, I attended the Dementia Care conference, sponsored by the Alzheimer's Association. That year, there were many plenary and workshop sessions devoted to philosophies of person-centered care, and I attended several of them. Person-centered care has a multitude of perspectives and strategies associated with it, however it is typically employed in the situation of advanced dementia, when an individual is less able to express him or herself in typical ways. There is ethnographic evidence that person-centered care philosophies in institutional settings produces better outcomes for the resident (McLean 2007). Given that the Dementia Care conference has many facility administrators, special care unit managers, recreation and occupational therapists, and nurses in attendance, this was an especially well-received theme in 2006.

I attended the conference again the following year, largely to track this development, what Cohen has termed the "personhood turn" (Cohen 2006; Cohen 2008). In 2007, however, the Alzheimer's Association had made a different commitment. Instead of the many discussions of person that existed the year before, the conference commitment in 2007 was to make visible the voices of people with Alzheimer's Disease, in the early stages. The events that drew excitement were those that included people with Alzheimer's Disease as speakers, or workshops that detailed how to enact services and

programs for people with Alzheimer's Disease, typically residing outside of institutional settings. This had been a commitment of the Alzheimer's Association for the year. They held four Town Hall Forums throughout the country, beginning in Oakland, where people could gather and discuss living under the description of Alzheimer's Disease, as people with the diagnosis. The mood in the conference that year was celebratory, and many remarked upon how inspirational these new representations and engagements could be.

As someone interested in the personhood turn, I felt this shift in focus as an eclipse. I came to understand this shift as a sea change in representation of Alzheimer's Disease that was both a response to demographics and the boomer generation's anxieties, as well as a political effort to reinvent Alzheimer's Disease for the consuming public. A staff person for the Alzheimer's Association commented:

> The voices, the faces, the problems, the policy issues are different. But it's the presence of persons who can advocate for themselves as opposed to caregiver advocates, both professional and family caregiver advocates, on behalf of somebody. It completely enriches the movement. It also calls for us to to think differently about, even internally, about people with Alzheimer Disease because they're looking for engagement and ways to create their way of coping with the disease and they're way of advocating for the disease so it's not enough to plan *for*, but now we're planning *for* and *with* persons with Alzheimer's Disease and that's creating all kinds of ruction because you know we got all these social workers and all kinds of other professions that think they know, and they do know but they don't know. […] So it's a double edged sword. But from an advocacy and public awareness perspective it's huge! […] It's putting a different face, and when that face is able to advocate for themselves it changes the equation. […] It's probably the biggest boost in our advocacy ranks in the last five years, have been our early stage people and it just creates metanoia. No longer is it that other, that eighty five year old who's all washed up anyway. It could be me, and you know what? I'll take people acting out of their own selfish interest if that's what it takes.

It would be very difficult to argue against this new practice. Representation by people living under the description of a disease is practically a right in a democracy with

a health care politics that relies upon disease-based advocacy. Representation, in this case, is an ethical engagement with a diagnosed other. However, I document this as an important transition that may well have proliferating effects for those who were, in the celebratory moment of inclusion, excluded: the others who cannot represent themselves easily, the others who are pointed to with terror. They make a far less compelling advocacy story.

Over the course of my fieldwork, I witnessed one self-advocate in particular on several occasions, telling her story of Alzheimer's Disease. In her fifties, she was poised and charming. Apparently comfortable speaking in public, she talked candidly of her diagnosis experience and the support she had received. She also talked about her daily life, which she described as lonely. Retired now from work, she comforted herself with writing and singing. I saw her participate in panel discussions, in presentations with her husband, and as a solo speaker. Over time, and perhaps because of the multiple engagements, I came to understand these moments as a new kind of case demonstration. Unlike the celebratory presentations by people with Down Syndrome that emphasized ability, made frequently and often at Down Syndrome conferences, the performance of a speaking and thinking person with Alzheimer's Disease is made visible for the primary purpose of demonstrating disease. Her presentations, voluntary of course, demonstrated both a surprising ability (given her diagnosis and its associated image) but also decline over time. Although I knew that I was one of the very few people in the room who had seen her perform on several occasions, I grew increasingly uncomfortable with what began to feel voyeuristic.

In an interview with a self-advocate and person with Alzheimer's Disease, I asked her what the world would look like without Alzheimer's Disease. She responded:

> It would be a world where – I have to think a little bit about that. (pause) Where people could be themselves and express themselves without having to worry about. […] Without having to apologize or feel bad about themselves or feel guilty for some reason. I think that there's a stigma to Alzheimer's that's different from other kinds of medical conditions that people have. Like breast cancer for example. People don't feel embarrassed by breast cancer, and that's a terrible disease a lot of people die from. And this is very personal to me I was always very competent, I always had good jobs, I enjoyed what I did and I was rewarded for what I was able to do. And you lose a lot of self-esteem in a situation like this. And I think that's been. I'm not sure I don't remember exactly how you framed the question but I think that's been real difficult for me.

Arguably, the world she describes might be made without altering the pathology or pathologies associated with Alzheimer's Disease one bit, as this advocate is speaking towards a problem located in the social construction of physiological trouble.

The movement towards including people with Alzheimer Disease is an important and much-needed shift in advocacy. My concern about this phenomenon is not that it is happening, but how. My questions center on whether or not this is inclusion, or performative politics as usual through representation, albeit new representations, of living under the description of Alzheimer Disease. These questions turn on the disease-based orientation of advocacy, the powerful position of the Alzheimer's Association, and the cultural urge towards competence as criteria for belonging.

Neurodiversity?

Given the transformations in diagnosis acquisition, population demographics, and public representation, a good question to ask is whether or not a new and different

Alzheimer's Disease is in the making. Arguably, earlier diagnosis at younger ages is the result of the collaborations of the clinical and scientific gaze that calibrate difference along a continuum of memory. This reach of the clinical extends earlier into adult life than has typically been imagined for Alzheimer's Disease over the past thirty years. Diagnosis of Alzheimer's Disease, Mild Cognitive Impairment, and even normal aging with subjective complaints are the result of a memoro-politics that contributes to the production of identities, politics, and perhaps even social change. It may be worth contemplating that neurodiversity is in the making, but largely through the production of knowledge and memory sciences. This counters an activist discourse that designates nature and general population diversity as the ultimate cause of neurodiverse ways of being. In the case of Alzheimer's Disease, neurodiversity comes into view through notions of pathologic change, and attempts to control and intervene.

CHAPTER FIVE: MAKING NORMAL

It's a great day to have Down Syndrome!
[…] You all, he is our knight in shining armor!
Introduction made by a parent of a young child with Down Syndrome for Dr. William Mobley at the National Down Syndrome Congress in Kansas City, 2007

People with Down Syndrome shouldn't be the lab dogs for Alzheimer's Disease.
Interview with a clinician serving people with Down Syndome, who was quoting a parent advocate

These two statements reveal the contradictory stakes of parents and other advocates regarding scientific investigation into both cognition and Alzheimer's Disease among people with Down Syndrome. The first statement, publicly offered to an interested audience of parents, suggests the perceived possibilities for scientific research and the faith in science as a pathway to knowledge and intervention. It also suggests that the cognitive difference encountered in Down Syndrome is a predicament from which parents, in particular, need to be saved.

The second comment, made in the relatively private setting of an interview protected by anonymity, suggests that skepticism of science and its use of people with Down Syndrome as models for knowledge exists simultaneously with faith in science in the scene of advocacy and clinical intervention. That the clinician quoted a parent to express his or her own views in a dynamic and dramatic way also points to the power that parents as advocates have in the social scene of advocacy.

Both of these commentaries engage with philosophies of how people with Down Syndrome should or should not be treated in society. These statements reveal encounters with the ethical that those living under the description of Down Syndrome but do not in fact have the condition endure and take up in their advocacy activities. In Chapter Three,

I closed on the ACOG recommendations and their rippling effects throughout advocacy for Down Syndrome. What is often at stake, playing an important role in the decisions made as a result of pre-natal diagnosis, are the perceptions of cognitive difference and disability associated with Down Syndrome.

Advocacy narratives have held out alternative horizons to prospective parents through the demonstration that the future for babies born now with Down Syndrome can be very different than what is typically imagined. With conference themes oriented around dreams, imagination, and possibility, hope for culture change and increased opportunity for people with Down Syndrome is cultivated. If the historical tactic of oppression and exclusion is to make claims that certain groups are not human or smart enough (Baynton 2001), advocacy in this arena pushes through this essentialism, metaphorically packing a one-two punch and effectively exclaiming, "You ain't seen nothing yet."

This stance relies deeply on discourses of improvement and progress in order to sustain momentum. Given the rapid change in practices associated with inclusion and intervention, "improvement and progress" are demonstrably made real through extended longevity and increased capability enjoyed by those living under the description of Down Syndrome. As one longtime scientific researcher noted to me, "Keeping kids with Down's syndrome out of [state hospitals] – you know, that was worth 20 IQ points. Just the institutionalization, nothing else, just being in a more normal environment is worth, cognitively, worth a lot. Sometimes social changes make an enormous difference, and I think we're seeing that. " Given that cognitive difference is often understood to be the defining problem associated with Down Syndrome, deinstitutionalization as a practice

associated with caring for individuals can also be seen as an intervention with curing effects.

Shortly after the American College of Obstetricians and Gynecologists (ACOG) issued their recommendations for extended prenatal testing, Amy Harmon published an article in the New York Times reporting on the responses of advocates to the new guidelines (Harmon 2007). In the article, Harmon interviews mothers who are working through advocacy to educate clinicians and prospective parents who have received a prenatal diagnosis of Down Syndrome. They report concerns on multiple levels: they want friends for their kids in a world where the number of children with Down Syndrome are diminishing; they work toward enough numerical visibility such that support resources will continue to be provided by society to their children; and they see a strength in numbers such that there will be more opportunities for their children as they grow into adulthood (Harmon 2007).

The situation of expanded testing, plus the routine statements of susceptibility and risk for Alzheimer's Disease in adult life now made regularly in genetic counseling sessions associated with pre-natal diagnosis and diagnosis at birth (all the parents of young children I met were aware of the associations between Down Syndrome and Alzheimer's Disease), the urgency of cultivating improvement hopes for lives well lived under the description of Down Syndrome has never been higher. Under the shadow of the dual irony of beginning and end of life susceptibilities, cognitive enhancement pharmaceuticals for the treatment of cognition among individuals with Down Syndrome are currently being explored by some scientists.

In this chapter, I highlight one public scientific talk centered on the cognition of individuals with Down Syndrome, possibilities for their cognitive enhancement, and the situation of Alzheimer's Disease and Down Syndrome. This public lecture serves as a lens toward understanding the extension of science in public debates associated with Down Syndrome advocacy, the ongoing project of a legitimation of science as powerful authority, and the very interesting turns toward disease-based advocacy that can be taken when science involves itself in the unfolding story of advocacy and intervention for Down Syndrome. At the heart of this lecture performance is the perception that parents have become what Michel Callon calls *obligatory passage points* in the production of scientific knowledge in the area of Down Syndrome (Callon 1986). As *obligatory passage points*, parent-advocate approval, support, and action is required in order for this science to proceed. I will argue that the lecture is one moment of persuasion where this pathway and approval is actively sought. This moment of persuasion will be refracted through the multi-decade history of parental practice of alternative treatments, especially vitamin supplementation marketed specifically for Down Syndrome.

COGNITIVE ENHANCEMENT and EXPERIMENTATION

Parents as Experimenters

While waiting for a lecture to begin at the National Down Syndrome Society conference in Chicago 2005, and through chatting with my neighbor, I was introduced to the use of the drug piracetam and drugs specific to Alzheimer's Disease such as Aricept and Namenda in people with Down Syndrome for the purpose of cognitive enhancement and the prevention of Alzheimer's Disease. I was initially very surprised at this off-label

use of Aricept and Namenda, because these drugs are not considered preventive for Alzheimer's Disease in the general population and they are also expensive medications associated with a variety of side effects. Gazing across the room, and taking in the range of ages of individuals with Down Syndrome who were present, my neighbor commented that her daughter, who was very young, would probably not experience Alzheimer's Disease because of these and other interventional strategies that many children with Down Syndrome now experience. These strategies include vitamin supplements, behavioral, language, and learning therapies. Excited about these developments, her perspective reflected a hope for progress through these technologies, as well as a better future for her child and others in her generational cohort. She considered the younger cohort exempt from the situations contemporary adults with Down Syndrome faced.

As my fieldwork progressed, I heard about these practices from other parents at conferences, and in interviews with scientists, clinicians, and advocates. I also learned that these practices, particularly piracetam, drugs associated with Alzheimer's Disease treatment in the general population, and the use of nutritional supplements specifically designed for those with Down Syndrome, were controversial. Both of the major national societies devoted to advocacy for (and by) people with Down Syndrome publish position papers concerning nutritional supplementation on their respective websites, and neither of them endorses these therapies. Each organization expresses concern about the potential to harm individuals with Down Syndrome, citing a lack of scientific evidence and systematic investigation as the grounds for suspicion. The National Down Syndrome Congress comments:

> To date, no vitamin or mineral nutritional supplement is known that will significantly alter the intelligence, physical characteristics or behavioral features of Down Syndrome and, thus, none are supported by the National Down Syndrome Congress.
>
> NDSC 2009

The position statement of the National Down Syndrome Society is equally strong (NDSS 2009a), and an additional informational resource on their website concerning alternative therapies advises parents to consider many things when deciding for or against them, including "think about negative stereotypes in our society and why we often feel the need to 'fix' the person with Down Syndrome" (NDSS 2009b). The Canadian Down Syndrome Society expands upon this with the following:

> Down syndrome is a naturally occurring chromosomal arrangement that has always been a part of the human condition. The occurrence of Down syndrome is universal across racial and gender lines, and it is present in approximately one in 800 births in Canada.
>
> Down syndrome is not a disease, disorder, defect or medical condition. It is inappropriate and offensive to refer to people with Down syndrome as "afflicted with" or "suffering from" it. Down syndrome itself does not require either treatment or prevention.
>
> The sole characteristic shared by all persons with Down syndrome is the presence of extra genetic material associated with the 21st chromosome. The effects of that extra genetic material vary greatly from individual to individual. Persons with Down syndrome karyotypes may be predisposed to certain illnesses and medical conditions, but that genetic arrangement does not guarantee their development. The same illnesses and conditions are also present in the general population.
>
> CDSS 2009

Dr. Len Leshin, a US medical doctor who is also a parent of an adult with Down Syndrome, critiques supplementation and other therapies on his website and on a medical website devoted to educating the general public about interventions that may either be compromised or fraudulent (Leshin 2009). He notes that the marketing techniques

associated with promoting the supplements misrepresents Down Syndrome as a disease that is both progressive and degenerative, leading to premature death, and that those marketing the supplements prey on a parent's worst fears for their child. Dr. Leshin argues that this is contrary to the historical experience of increased longevity and quality of life for individuals with Down Syndrome in which supplementation is not implicated as a cause for these improvements (Leshin 2009).

It is not my intent, or within my capability, to determine the extent to which these therapies are efficacious. As many have pointed out to me through interviews and discussions, the question of whether a child's development has been enhanced through supplementation or medication is very difficult to ascertain, due to the fact that the child would have grown, changed, and developed regardless of any intervention pursued, coupled with the extreme variability expressed through the trisomy of Down Syndrome. Indeed, the effects of supplementation are very difficult to parse in general. What remains interesting, however, is what the penetration of these technologies reveals about their users. Parents have been experimenting with processes associated with cognitive enhancement for decades, and through mechanisms with extended reach through the rest of American society.

Dietary supplements are a multi-billion dollar industry in the United States, and this is largely facilitated through the degree of governmental regulation it commands since the DSHEA (Dietary Supplement Health and Education Act) of 1994. Medical anthropologists Mark Nichter and Jennifer Jo Thompson argue that supplements are scarcely regulated, and are considered neither a food nor a drug through the DSHEA. They are regulated primarily for the claims they are permitted to include on their labels

(Nichter and Thompson 2006). As commodities devoted to self-health technologies, users experiment with supplements using a wide range of rationales, from health production to harm reduction, and with a sense of both safety and efficacy through their efforts (Nichter and Thompson 2006). Drawing from the work of Michel Foucault and Nikolas Rose, Nichter and Thompson note that the use of supplementation "blurs the distinction between health management and enhancement" and is "part of a larger self-governance project, in which responsible citizens are attentive to changes in the relative state of their health, carefully monitor such changes, and express concern through health-related practices," a project which serves to emphasize the individual and drive enterprise in a neoliberal society (Nichter and Thompson 2006: 180, 209). As a practice, nutritional supplementation and its related discourse of health benefit through intervention at the level of molecular interaction and body mechanisms in the United States is very familiar. These parents, like many others in the United States, reach for the molecular with hopes that it will extend their lives – or the lives of their children – into the normal.

Anthropologists Erica Prussing and colleagues studied the use of complementary and alternative therapies among parents of children with Down Syndrome, troubling the way that the parents' critics interpret motivations for using nonconventional therapies. They note those clinicians and others who are skeptical of the success claims of supplement marketers and their users often assert that parents use these therapies because they are "desperate" (Prussing et al 2005). I also heard this type of commentary in my interviews with clinicians and scientists, who often regarded the parents who chose supplementation to be desperate and suffering in a society that disregarded both their child and them. However, Prussing et al's analysis of narratives provided by parents

detailing their choice to explore alternative therapies does not suggest that the parents were desperate. Instead, they argue that parental choices reflected congruence between their own priorities and values for their children, and the priorities and sentiments embedded within the alternatives that were sought. Nutritional supplementation and other alternatives were explored by parents as a way to construct alternatives to the idea of life under the description of Down Syndrome as a "fixed, universal, and essentially pathological course," and that the evaluation of alternative therapies constituted a new discursive resource for asserting human rights for their children, as well as establishing themselves as morally good parents (Prussing et al 2005: 587-588). Through my conversations with parents at conferences who used these supplements and medications, it became clear to me that "desperation" was an inadequate adjective for the parents who confidently spoke of the choices they had made for their children. Through the stories they told, they expressed a hopeful attitude and a certainty that they were doing all that they could. Their claims that supplements and other pharmaceuticals were efficacious appeared to be unwavering.

It was just such a supporter of supplementation and pharmaceutical treatment, and long time advocate for individuals with Down Syndrome, who referred me to Dr. Lawrence Leichtman (permission granted to use his actual name). Dr. Leichtman is a clinician who recommends Nutrivene-D, a popular supplement specific to Down Syndrome, as well as piracetam and the pharmaceuticals often associated with Alzheimer's Disease, Aricept and Namenda. Dr. Leichtman is also President of the Trisomy 21 Research Foundation which, not too surprisingly, is noted on the Nutrivene-D website as a recommender of their products. The Nutrivene-D website, in turn,

promotes Dr. Leichtman's practice and lists the Trisomy 21 Research Foundation recommendations for supplementation as a downloadable pdf.[4] In my interview with him, Dr. Leichtman stated that there was no financial relationship between the two entities, the producers of Nutrivene-D and his clinical practice.

Dr. Leichtman has enacted a clinical practice style sought out by his predecessors in the field of nutritional supplementation and Down Syndrome: for much of his career, he has been a traveling doctor who holds occasional clinics in many regions of the United States (according to his website, this practice of travel ceased in December 2009). I met with Dr. Leichtman in a modest hotel where he and his wife were staying during one of his California clinic visits. We sat at the small table in the crowded motel space, and as his wife packed for their return home we conversed about his clinic, his rationale for intervention, and the history of nutritional supplementation.

The history that Dr. Leichtman offered is easily accessed through an internet search, where a plethora of short biographical histories of supplementation and stories of successes can by found by the interested parent or anthropologist. Dr. Henry Turkel, in the 1940s and prior to the identification of trisomy as the cause of Down Syndrome, advocated for the use of vitamins, minerals, and enzymes to treat children with Down Syndrome. He developed a formula called the U series, and treated people with Down Syndrome for nearly forty years with this supplement. His formula included thyroid hormone, and was offered to patients with Down Syndrome at a time when they were not routinely evaluated for hypothyroidism, to which they are prone. Detractors often point to

[4] I have repeatedly conducted internet searches for more information on the activities of the Trisomy 21 Research Foundation and have found very little, except that Dixie Lawrence Tafoya founded it, the mother of a child with Down Syndrome who developed the formula.

the addition of thyroid hormone in the formula as the contributing element leading to the improvements he observed and documented in his patients. Recently, in 2007, Dr. Henry Turkel was posthumously inducted into the Orthomolecular Hall of Fame. In the program for the ceremony, nobel-laureate and often-cited "father of molecular biology" Linus Pauling is cited as having been a supporter of Turkel's therapies, and Abram Hoffer is quoted:

> Dr Turkel had the nerve to make his claims when everyone 'knew' that children with genetic defects could not possibly be treated successfully.
> Abram Hoffer, Orthomolecular Hall of Fame program 2007

The late Dr. Jack Warner followed in Dr. Turkel's footsteps with a version of the U Series that he called HAP caps, coupled with a multidisciplinary approach to wellness that included physical and other therapies. Dixie Lawrence Tafoya, mother of a child with Down Syndrome, developed the supplement that Dr. Leichtman recommends, Nutrivene-D. A widely publicized television interview in 1997 garnered the spotlight for Nutrivene-D, as well as the often-added use of piracetam. This special report, which interviewed both supporters and those skeptical of the treatments, highlighted Tafoya's configuration of Down Syndrome as a degenerative disease that deserved attention and treatment, as well as the opposing view that it is not a disease warranting treatment at all. For those who argue the latter perspective, it is society that needs to learn to be more accepting of differences, and their children are fine as they are (CBS 1997).

A thorough historical treatment of nutritional supplementation for individuals with Down Syndrome would be a welcome addition to the literature on Down Syndrome generally. This is not such an attempt. It is important to note, however, that through this kind of story it becomes apparent that the legitimized purveyor and recommenders of

these supplements have historically been doctors. This reflects that these practices fit rather solidly under the umbrellas of medicalization or biomedicalization and are not entirely an opposition. Rather than represent something thoroughly "alternative," it would be more accurate to construe activities emphasizing nutritional supplementation as occurring on either side of historical fault lines *within* medicine and science. Correspondingly, the practice of including a physician in the dispensing of these treatments is an activity of their social legitimation. In the case of Dr. Leichtman, he describes being pulled into his clinical service towards Down Syndrome and its supplementation by Tafoya and then other parents, a narrative which resonates with those of other clinical providers I interviewed who describe the advocacy of parents as a catalyst for their own specialization in Down Syndrome. From the perspective of parents, they take their children to specialty doctors and receive syndrome-appropriate and targeted treatment that they hope is efficacious for them.

These specialized supplements are an ongoing cost, paid privately, and expensive for many. Currently, the Trisomy 21 Research Foundation recommends a suite of supplements (Nutrivene-D, daily supplement, enzymes, and a night-time formula plus Vitamin D, DHA/EPA, Ginkgo Biloba, Nutrivene Longvida Curcumin, Probiotic, Piracetam or Aricept or Namenda), most of which can be purchased for a total ranging from $200 to $235 from the Nutrivene website (http://www.nutrivene.com, February 7, 2010). Aricept and Namenda, medications associated with Alzheimer's Disease treatment protocols, require a physician prescription and, for the uninsured, are very expensive drugs. Piracetam is available in a Nutrivene formulation as a supplement. This cost of approximately $200 might cover a supply for 45 days to two months. Over the course of

my fieldwork, I heard a range of casual estimates from clinicians and scientists suggesting that between 40% to 80% of parents in the United States with the resources to pay for supplements try them at least once during their child's development. Dr. Leichtman's estimate was the lowest, at 40%. One doctor, who maintains close ties to parent advocates, thought that the supplements did not do much good, but that they likely did not do much harm either. He offered this opinion candidly to parents, but also invited them to tell him the choices they were making with regard to these and other treatments in an effort to facilitate an honest dialogue concerning these practices.

As this suggests, some parents have been experimenting with cognitive enhancement for quite a while, despite the non-endorsement of major national advocacy and information organizations, and the opinions of conventional medicine. Additionally, the very idea of treatment requires a deficit or disease-based model for Down Syndrome that stands alongside an advocacy movement that argues for acceptance and inclusion based upon the idea of variation and human diversity. Thus, the idea of pursuing treatment for the cognitive differences associated with Down Syndrome is not entirely new, nor are some parents opposed to it. Indeed, some not only pursue nutritional supplementation, but also pharmaceutical products associated with the treatment of Alzheimer's Disease in the general population as a cognitive enhancer and preventive effort. Through their ongoing experiments, not only in the arena of supplementation but generally in their efforts to parent and advocate, parents have accrued a sense of biomedical authority and expertise among themselves.

SCIENCE, MEDICINE, AND PARENTS: OF MEN AND MICE

Over the past forty years, parents living under the description of Down Syndrome have claimed both authority and expertise in the care of their children. First, in the 1940's they began to resist once-dominant medical opinion that institutionalization was the best management tool for both parent and child (Trent 1994), and then they became advocates in the clinic for their children's complex medical needs. This has as much to do with living under the description of Down Syndrome themselves as it does with the biological and socially embodied situation of the genetic trisomy. It was parents as individuals, and in groups, who advocated for the rights to existing treatments for their children when it was not customarily offered them. And it was parents who pulled certain doctors into their midst as advocates and allies.

Now, parents of children and adults with Down Syndrome often have a contentious yet dependent relationship on medicine, an outgrowth of medicalization. From the first moments of life and throughout life these parents are enrolled into the rubric of medicine in caring for their child to a degree often not experienced among parents of typically developing children who have no major health concerns. Down Syndrome often enough yields multiple medical anomalies and pathologies, for which treatment (and often surgery) is required in order for the individual with Down Syndrome to remain alive in the world and grow into adulthood. Medicine has moved from a stance of non-intervention to one of extreme intervention, often requiring specialists such as cardiologists, neurologists, or endocrinologists. Not only is the child medicalized, but the parents are too, living as they are "under the description." We have seen this in Chapter Three, in reference to pre-natal testing and care. However, tensions with medicalization

do not end with the pre-natal encounter, and extends into childhood and adult life. Frustrations abound in finding doctors who respond to parent advocacy efforts, and this has been the impetus for developing Down Syndrome specific clinics and expertise. Parents are often concerned that their children are either under treated or miss-diagnosed. This is keenly felt in the area of Alzheimer's Disease diagnosis for people with Down Syndrome.

Often enough this ambivalence extends to science as well, such that one woman can exclaim publicly in a conference workshop:

> One woman stood up and talked about her son, who was seated beside her. She talked about being a parent of an adult with Down Syndrome and how successful he was. She talked about how when he was very young, she enrolled him in every study possible. She emphasized that research was important, but that it was the job of the researchers to do research. She said that she had turned her son into an object during that time, even for herself. And she said that turning children into objects was not a good thing. Emphasizing again that research was important ("we need it") she also talked about the importance of her son as a person in the world, someone not just with Down Syndrome.
>
> Field note: August 23, 2006

Some activities of science can seem suspect to parents because of the customary use of animal models and the descriptions of scientists that suggest that people with Down Syndrome are models for Alzheimer's Disease, touching on the historical and deeply sensed last nerve of the distinctions between human and animal that people with Down Syndrome have endured. A young scientist, in an interview with me, recounted a surprising moment for her when volunteering at a booth devoted to science in a larger event about Down Syndrome. Without stopping to find out what the science booth offered, a mother declared in an angry voice to her friend as they walked by, "My son is not a mouse!"

Correspondingly, the way that scientists talk about models can result in conflict or tension. For example, in a public lecture at the World Down Syndrome Congress in Vancouver, Dr. Ira Lott, of the University of California at Irvine, spoke of modeling in this way (from transcript, August 24, 2006):

> Now the next piece of evidence about oxidative stress comes from dogs. There is a type of beagle dog that gets Alzheimer's Disease. Now, I don't know a lot about dogs. People tell me that beagles are not too smart to begin with (people laugh). I apologize if anyone has a beagle. But there's a certain type of beagle who becomes demented and develops Alzheimer's plaques. And these have been studied all over the world and there's an investigator at Irvine who has also studied them. And here's the beta amyloid deposition in dogs in comparison with human brain. These are the stages of amyloid deposition in dogs. And here is Down Syndrome. Thirty one years, forty years, fifty four years. So you can see oxidized abeta is present through this whole system.

His description of the beagle as "not too smart to begin with" and also susceptible to developing Alzheimer's-like pathology, immediately juxtapositioned with images of similar pathology in the brain of someone with Down Syndrome could pose a problem for a parent advocate who might be concerned either about how Down Syndrome is being used in research (as a model or an object), or about the accrual under the description of Down Syndrome of yet another stigmatizing condition associated with cognitive incapacity.

Dr. Lott commented in his lecture that, "We now have a working group of about fourteen neuroscientists and I think that speaks to the compelling problems and challenges and potential understanding that people with Down Syndrome have for understanding the basic mechanisms of neuroscience and also Alzheimer's Disease." In an interview with me, another scientist spoke on the topic of Down Syndrome as a model for Alzheimer's Disease:

> Using Down Syndrome models we're probably learning a great deal about what goes on in the AD brain. And I think we're in a position not just to learn that little bit in the laboratory but to really make it relevant clinically. […] I mean we can diagnose Alzheimer's now in a newborn that has Down Syndrome. We know that the pathology will develop in time and we now have a forty-year window to collect data that speaks to pathogenesis and cause and affect and theoretically might speak to prevention. So I think we have maybe the world's most perfect population to study the pathogenesis of Alzheimer's Disease or at least Alzheimer's related neuropathology.

Although this may accurate from the perspective of science, one can also discern the skepticism a long-time advocate might feel upon realizing that Down Syndrome becomes a beneficial object for science when it is perceived useful for the general population, and in unpacking the "disease of the century," Alzheimer's Disease. The sentiment, "People with Down Syndrome shouldn't be the lab dogs for Alzheimer's Disease" becomes easier to understand.[5]

In contrast, a mother who has treated her adult son with Down Syndrome for several years with Nutrivene-D and Aricept commented to me following an interview (paraphrased, and from my fieldnotes), "research coming out of [a major research center] now is saying the same thing, but *we've* been doing this for years! But they need all these double-blind trials and all. Before long, they will all be doing it. It's a shame really. They should all work together, but they don't. The medications and treatments don't take away mental retardation and they don't take away the Down Syndrome, but they really help."

[5] Cohen has developed a concept, *bioavailability*, to refer to the availability of tissues and organs for selective removal from one body and placement into another body. He uses this concept to think through organ transplant practices (Cohen 2007). The possibility of using the bodies and brains of people with Down Syndrome over their life course to produce knowledge about Alzheimer's Disease is an example of a kind of *bioavailability*, albeit without the direct and practical transfer of tissues from one body to another. Although not discussed in this thesis, the complexity of the relationship between Down Syndrome and Alzheimer's Disease could be productively reviewed with the assistance of the analytic, *bioavailability.*

This commentary suggests that some parents think that they are ahead of the curve, with scientific investigation lagging behind due to its costly and difficult methods of producing knowledge through the clinical trial. The question of expertise – who knows what about Down Syndrome – is a tension centered often in the dialogue between parent and clinician, and also vis-à-vis the movement of scientific research.

Joking about the concept of normal is one example of how tensions are demonstrated throughout advocacy talk. In an interview with a long-time advocate, he remarked, "You know, my one son was diagnosed with Down syndrome and my other son was diagnosed with normal. Thirty years later I know more about Down Syndrome than I do about normal! I'm still not quite sure what that means." Publicly, Patricia Bauer – journalist, advocate, and mother of Margaret, an adult with Down Syndrome – said in a plenary speech at the National Down Syndrome Congress in Kansas City:

> I'm sure I'm not alone in saying that for the first few years of Margaret's life we worked very, very hard to do everything we could to help Margaret become "normal." It was only later that we realized what most families get to eventually: that "normal" wasn't the point. Our real goal was to help Margaret be Margaret. It was only by letting go of the concept of normal that we were able to see our daughter as the delightful person that she truly is, not obscured by some burdensome word, some arbitrary social ideal that had nothing to do with any of us.
>
> Like it or not, though, we have to admit that we as a nation have been sold this concept of "normal," and we've fallen for it. Somehow, while the disability community was out of the room, the world of medicine established a diagnosable standard called "normal" and now we're all trying as hard as we can to achieve it.
>
> Patricia Bauer, August 5, 2007

Commentary about normal, especially that which pokes fun at the concept, customarily draws chuckles from advocates. Part of the experience of living under the description of

Down Syndrome seems to be about deconstructing the norms of the larger society, especially with regard to expectations of individuals in terms of intellect. However, the forms of society often enough go unquestioned.

The two national advocacy organizations, the National Down Syndrome Society and the National Down Syndrome Congress, reflect the felt tensions parents often have with science and medicine in their parenting projects. The tensions were evident at the World Down Syndrome Congress as well. All three of these organizations, as well as the events they sponsor, are family based with conferences that include parents and their children with Down Syndrome from infant to adults. Each of the United States-based organizations arranges an annual conference schedule that includes topics ranging from early child education, medical issues for individuals with Down Syndrome, political advocacy, higher education and job acquisition, to the current science of Down Syndrome. Each includes a parallel conference for adults with Down Syndrome. Although parent members often cite important differences between the two organizations in philosophy and scope, each conference includes similar if not often the same set of speakers, including representatives from the other organization in their public presentations. To a casual observer, these events do not appear to be markedly different despite the discerning eye of parents and their choices to be an involved member in one or the other group. Some prominent advocates are involved in both, and there is very little territorial behavior with small and local Down Syndrome groups. In fact, many of the local groups affiliate with both of the national organizations simultaneously.

Parents who have been involved in advocacy for a long time tend to regard these two organizations as distinct with regard to science and medicine. Generally, perceptions

seem to be that the National Down Syndrome Society is oriented towards science and the National Down Syndrome Congress is more oriented to their primary constituencies – people with Down Syndrome and their families. Indeed, the National Down Syndrome Society, explained to me by a multi-decade advocate, was founded under the philosophy that more science was needed in the area of Down Syndrome and as a break off group from the National Down Syndrome Congress. However, this advocate also noted that in today's environment, the two groups were beginning to converge and even swap places, with the Society pursuing more direct advocacy for people with Down Syndrome and their families, and the Congress exploring the possibilities science had to offer. Indeed, the science lecture highlighted later in this chapter occurred at the Congress advocacy conference, and the speaker, Dr. William Mobley, was honored with a distinguished award at the conference banquet. Interestingly, parent advocates who are relatively new to the scene of advocacy for Down Syndrome do not note the distinctions between the two groups, and instead occasionally express puzzlement that there are two.

At the World Down Syndrome Congress in Vancouver, BC, participants regularly commented to me and to each other that they thought that the conference itself was "too science-y." Despite the fact that the plenaries appeared to me to be quite diverse in orientation, and even included history and advocacy issues, this opinion by many participants was strongly held. Indeed, as the days of the conference progressed, the audience for the plenary sessions dwindled to a very small group. One woman elaborated that she really just wanted information that told her what *she* could do for her child. Scientific commentary on neuronal pathways, psychological hypothesizing about learning and the brain, or statistical surveying of capacity were not things she perceived

to be helpful to her or relevant for her child's life. This is reflective of a comment made in an interview by a clinician expert on Down Syndrome, "what do parents find as problems? That's what you have to solve! Don't do something that you can do just cuz you can do it, which is the typical role of science."

As the story of cognitive enhancement through supplementation and medication demonstrates, parents have been actively involved in seeking out strategies and practices that they feel will assist their child in development and achievement. It is in this complicated historical terrain of practice, experimentation, and skepticism that scientists now traverse to gain their own toehold, to court their own allies, defenders, and fundraisers in the pursuit of a science that is now interested in the questions one might ask and gain answers for through Down Syndrome.

The history of experimentation with supplements and medications that are perceived to enhance and improve upon an existing bodily substrate is not unique to Down Syndrome. However, enhancement practices pursued in the name of either Down Syndrome or generally to cognitive disability is subject to unique commentary, often grounded in tropes of contemporary life and its many conundrums. During the course of my interviews, the science fiction novel *Flowers for Algernon* (Keyes 1975) emerged as a topic of conversation and an example of ethical considerations concerning cognitive enhancement among those who carry the label of mental retardation, as well as its fascination. For this reason, I will detail the Charlie's (science fiction) account of growing smart.

STORY: *FLOWERS FOR ALGERNON*, A SCIENCE FANTASY

Billed as work of science fiction, Daniel Keyes tells the story of a young mentally retarded man, Charlie, who is selected to be the first human experimental subject to undergo surgery to repair his brain and enhance his intellect. Initially, the experiment appears to be successful. He achieves genius status within weeks, learning several languages and becoming adept at high-level scientific concepts. Prior to Charlie's surgery, the experiment was performed on a white lab mouse named Algernon who became genius at running complicated mazes. As Charlie begins to revel in his new accomplishments, Algernon begins to display erratic behavior, suggesting that the effects of the surgery are not permanent. Charlie, concerned about this, researches and detects the flaw in the initial calculations, discovering that he, too, will regress back to his pre-surgery state with the very real possibility of regressing further than his original baseline abilities.

The story is told entirely through Charlie's diaries, begun just before his brain surgery. In these texts, the reader witnesses changes in Charlie's spelling, observations, and levels of intellectual sophistication. Charlie records not only his accomplishments, however. He also describes his feelings as he discovers, through dreams and memories, how he was perceived as an intellectually disabled man, customarily as less than human and the butt of a good joke. By the end of the novel, Charlie is moving to an institutional residence. Algernon, the mouse, has died.

Charlie spends his time, prior to his surgical enhancement, working at a bakery as a janitor and all-around errand person. His parents abandon him to his Uncle Herman and never contact him again. When Herman dies, his friend, who owns a bakery, promises to

"keep a dollar in his pocket and a roof over his head." When the reader meets Charlie, he has worked for the bakery for seventeen years in this capacity, lives in a room secured for him by the bakery owner, and gets along in his own life with occasional mishaps such as being abandoned while slightly drunk by coworkers or occasionally getting lost and requiring a policeman's escort home.

Charlie is chosen for the experiment because he has a strong desire to learn. He is selected from a community education classroom for persons with intellectual disabilities. He has learned to read and write at a minimal level through this classroom experience. Before his surgery, he expresses a desire to become smart and seems to be willing to work hard at it. He is also described as friendly and kind, treating most of the people he meets as friends. He eagerly engages in laughter, even at his own expense. His coworkers have an expression that refers to having done something foolish or dumb, "pulling a Charlie Gordon." Charlie, who knows that it refers to him, seems to welcome the expression.

In contrast to this representation of Charlie, his enhanced genius state is described by others, and then by himself, as egotistical, antisocial, arrogant, and intolerant. He judges the scientists he encounters to be fake and ordinary, realizing that his intellect far outstrips theirs. The last entry of Charlie's, when he has returned to his pre-surgery state, invokes his earlier orientation to friendship and laughter, deeming these aspects of person to be most important.

Charlie's rapid changes are not only detailed through intellectual projects. His journey is not simply one of learning and knowledge, but also of self. Through dreams, Charlie begins to remember. These memories inform him of his familial interactions and

provide a biography for Charlie that he previously did not have. Because the memories are now filtered through his enhanced brain, he is able to interpret them in sophisticated ways. Intrinsic to this story element is a theory of the mind of the person with intellectual disabilities. Despite his life history of a particular cognitive capacity, this story tells us that behind the mechanism that causes the disability is a perfect mind that remembers everything meticulously and truthfully. It only needs to be unlocked. This metaphor of an unlocking mechanism is also used in the text's sci-fi explanation for how the surgery worked. Brain and mind are coterminous with one another and mechanically oriented.

A dominant theme for Charlie is his realization of personhood, both before and after the surgery. He is indignant at those who treat him as if he were an experimental animal, taking particular offense at the principal investigator on the project. This scientist repeatedly comments that he has "made" Charlie. What Charlie insists upon, and eventually fights for, is that he always had been a human being, a person, even prior to surgery and that he and all other human beings deserve that consideration and respect.

The *Flowers for Algernon* story reveals some of the excitement and caution that builds around improving the cognition of people with Down syndrome through scientific effort. The project of cognitive enhancement was begun, and pursued, largely by parents through science obliquely – the rhetorical promises of vitamin supplementation are grounded in experimentation, albeit the experimentation of parents. From cell therapies (a highly questionable and potentially damaging therapy involving the injection of cells from animals into the person with Down Syndrome) to sign language, brainstorming and experimentation have occurred in the homes and schools populated by people with Down Syndrome. These activities have been motivated by the deep insistence in society that

these individuals be and become functional independent human beings in order to participate reasonably well in democracy and have rights. Indeed, the question of ability is at the heart of citizenship, and this advocacy group knows this very well.

So the emergence of legitimized science worlds to improve the cognitive capacity of individuals with Down Syndrome is worth questioning to great extent. Why now? Why is it important in today's scene to work toward this kind of improvement, and with pharmaceutical intervention? And how is this era of effort towards this end of cognitive enhancement different than the alternative experimental treatments that have preceded it?

EXTRA CHROMOSOME, EXTRA ALZHEIMER'S DISEASE

The theory of excess genetic material producing excess protein leading to pathology is a potent one for scientists theorizing connections between Down Syndrome and Alzheimer's Disease. In a public lecture designed for a non-scientist, and primarily parent, audience, Dr. William Mobley, Professor of Neurology and Neurological Science and Professor of Pediatrics at Stanford University, described the causal mechanism of Alzheimer's Disease in Down Syndrome, and the potential for developing a drug to eliminate its risk in people with Down Syndrome.

The lecture, enthusiastically introduced by a parent of a young child with Down Syndrome who declared Dr. Mobley a "knight in shining armor," was attended by parents whose children, as evidenced by their questions in the discussion that followed, varied in age from infant to adult but largely centered on young children and teenagers. Throughout the lecture there was a steady stream of babbling and occasional cries of

infants and toddlers. This was a typical scene at the family driven conferences organized by the NDSS and NDSC.

Using scientific drawings, and the visually stunning images of neurons and the movement of neurotransmitters along neurons, Dr. Mobley explained experiments conducted on the Down Syndrome mouse to an audience that murmured as if on cue to the beautiful and arresting display of image and form. Through these visualizations of neurons in the Down Syndrome mouse model, Dr. Mobley compared the typical mouse neurons to those from the Down Syndrome mouse model. These demonstrations provided visual evidence that in the Down Syndrome mouse model, neurons were of a different shape, had different structural features in terms of size and number, and that neurotransmitters moved more slowly along the neural axon. He compared the Down Syndrome mouse neuron to those acquired on autopsy from people with Down Syndrome, noting their similarity.

After establishing the mouse model and the human as homologous, Dr. Mobley detailed the experimentation and one current hypothesis concerning the causal mechanism for the acquisition of Alzheimer's Disease among people with Down Syndrome. Dr. Mobley argued that the problem leading not only to Alzheimer's Disease for people with Down Syndrome but also to the generalized difficulties in cognition that people with Down Syndrome experience was the extra copy of one gene, known as the APP gene. This gene is named thus because the protein it ultimately produces is the amyloid precursor protein (APP), a protein implicated in the pathway to creating amyloid which makes up the plaques customarily associated with Alzheimer's Disease pathology.

In the classic trisomy of Down Syndrome, trisomy 21, a person with Down Syndrome will typically receive an extra copy of the APP gene. Dr. Mobley postulates that this extra APP gene produces excess APP, which disrupts the transport of nerve growth factor along the axon, and stimulates the production of Alzheimer's Disease plaques in the brain. While the production of the plaques associated with Alzheimer's Disease are important to this thesis, the disruption of nerve growth factor along the neuron is of paramount importance. For it is in this disruption of the processes along the axon that Dr. Mobley links a causal mechanism of Alzheimer's Disease to the more generalized cognitive differences that people with Down Syndrome typically encounter. As a result, Dr. Mobley argues that a pharmacological intervention that could limit or disable the activities of this one extra gene would improve the cognition and general function of people with Down Syndrome as well as *eliminate* the incidence of Alzheimer's Disease from this population of people construed to be at-risk for it. Additionally, he tells his audience that he is already working in collaboration with a pharmaceutical company that has made a compound that shows some promise for accomplishing this, and that it could be to market in five to ten years.

As a nonscientist, I am not equipped to deconstruct the theorization I just described, except to note that linking the cognitive differences that people with Down Syndrome display, as well as their very wide variability, to the excess protein production of one gene seems rather simple. Many conditions associated with Down Syndrome, from hypothyroidism to often-undiagnosed hearing losses, affect learning and cognition, and it is possible to consider multiple pathways towards global cognitive difference, as well as

their timing of occurrence within development. Furthermore, any medication under study would encounter similar problems that nutritional supplements with regard to evidence.

Instead, my interest is in the rhetorical strategies he utilizes in this lecture to persuade parents away from their own practices and towards the work of science. Throughout his talk, he refutes their experimentation with supplements and off-label use of Alzheimer's Disease medication, admonishing them to wait for science to investigate matters thoroughly and effectively no less than nine times, and seeks their support by claiming to be their friend.

He argues that a pharmaceutical treatment, subjected to full clinical trial and therefore true, efficacious, and safe, will result in improved function. He states:

> So the question is what's my real goal. So my real goal is your real goal. Do you want your children to drive? Then I do. You want 'em to go to college? Then I do. Want 'em to get married? I do. Want 'em to use e-mail? I do. I don't want to change your children. The worst thing in the world would be for me to tell you oh my gosh I've come to save the day. No way. But I have come to help you. I have come to help you with your child reach those goals for your child that you care about most.

Dr. Leichtman commented approvingly in his interview with me that the scientists doing this work are finally using a disease model for Down Syndrome. By taking up a disease model, he argued, one can effectively treat Down Syndrome as both a metabolic and neurodegenerative disorder. Dr. Mobley relied heavily on the language of disease and disruption throughout his public talk at the advocacy conference. He utilized language such as "diseased," "sick," "disrupted," "dysfunctional," and "abnormal" in describing the generalized neuronal processes occurring in both the Down Syndrome mouse model, and in people with Down Syndrome. His use of the term "abnormal" was particularly marked, and he used it in reference to the distinctions he drew between neuronal

processes noted in the Down Syndrome versus typical lab mouse, as well as between the whole brains of people with Down Syndrome and the brains of those without Down Syndrome. Indeed, he utilized this language to speak to those features of living under the description of Down Syndrome that people and society have denoted as problems, and to lead to the possibility of solution through pharmaceutical treatment.

This is not remarkable given his scientific research interest and goals for intervention. However, what is anomalous is that he was making his speech within a context – a national advocacy conference devoted to Down Syndrome – where an orientation towards a dichotomy of normal versus abnormal is regularly eschewed and critiqued, and where people with Down Syndrome are described as entirely okay in and of themselves with regard to their cognitive capacities. In these contexts, the political and public rhetoric characterizes Down Syndrome as a cognitive difference with unique gifts and skills to offer the world, and yet here in this lecture a disease model was enacted with virtually no resistance or public commentary from the advocate audience of concerned parents.

Equally interesting is how the disease concept for Down Syndrome is taken up in matters of cognition. Historically, the situation of trisomy in Down Syndrome has been medicalized such that the activity of the extra chromosome produces various (and varying) disease states. Identifying individual diseases has had the effect of removing them from the definition of Down Syndrome. Instead, Down Syndrome is seen as a risk factor for them, but not the same as the diseases themselves.

In this case of researching cognition, however, there is no effort by Dr. Mobley in this instance or by other researchers to separate the differences associated with cognition

as a separate and distinct disease process. For example, he does not suggest that he has found a new disease associated with APP and neuronal disruption. Instead, Down Syndrome is not a risk factor but in fact the disease state for cognitive dilemmas. This reveals the emphasis on cognition, and cognitive disability, at the core of the social, cultural, medical, and scientific definition of Down Syndrome. Only when extended further out into the life course, and associated with a decline or change from baseline, does this become a separated disease, Alzheimer's Disease.

CURING DOWN SYNDROME: HOPE AND ANGST

"Miserable just like us."

During the question and answer period following Dr. Mobley's lecture, a mother asked him if the treatment he was proposing would affect or alter the "personality" of people with Down Syndrome. This construction of a Down Syndrome "personality" is developed extensively through advocacy talk, with the individual with Down Syndrome often described as essentially happy, kind, emotionally intuitive, social and gregarious, and prone to giving hugs and affection. It is through this description that unique skills and gifts perceived to be particular to people with Down Syndrome are delineated and valued, and a call for acceptance and diversity invoked. This questioning parent placed a positive valance on the personality type associated with Down Syndrome and communicated a reluctance to see it disappear with cognitive enhancement. Adding to her initial concern about personality, she said "and we talk about making them sort of more normal. How is that? I know that you're not, but where's the fine line of changing…" Dr. Mobley interrupted this last sentence, and responded to the concern, noting that he wanted the lives of people with Down Syndrome to be easier and less fraught with functional

difficulties, and adding that with respect to the issue of personality he wished that he himself were more like people with Down Syndrome. He concluded:

> Is it possible to enhance cognition and not have a change of personality? A betting man would say no. They might all end up just as miserable as you and I!

This evoked some chuckles and laughter, and he added:

> I'm hopeful that this chromosome is so powerful and so big that we can enhance cognition without destroying their love. So that's where I am on this thing. Let me just mention something about APP. I'm going to make this statement and it's probably over the top, it's probably wrong, but I'm gonna say I think we now have a clue that may make it possible for us in our lifetimes to eliminate Alzheimer's Disease in people with Down Syndrome.
>
> […] so I think that we have the opportunity to substantially lessen the consequences or even the occurrence of Alzheimer's Disease in your children and that is something I'll fight for because that's something all of us want. No one in this room wants to be sixty and have their child to face that as an almost certain future.

This rather complicated response links questions of person and personality concretely to genetics, the activities of genes, and ultimately one's cognitive state. Dr. Mobley introduces doubt and uncertainty ("a betting man would say no"), acknowledging that the use and effects of these pharmaceutical interventions cannot be fully divined or otherwise predicted. Positioning his research and impulse toward drug development on the edges of scientific knowledge, he expresses one of the historically powerful sentiments of modernity: that we are compelled to pursue a progress the consequences of which we cannot completely understand. In doing this, he invites parents to experiment with him in the pursuit of new possibilities in the experience of Down Syndrome, and of reshaping the experience of living under its description.

Dr. Mobley gestures toward the most prominent theme in the *Flowers for Algernon* story, the attribution of intellectual or cognitive capacity to one's ability to love or express kindness. In his response, he identifies misery with those who do not have Down Syndrome, and love (framed as an essential, universal, and collective "their love") with cognitive disability or reduced mental acuity from the perceived norm, grounded in the chromosome. Rhetorically, he separates the chromosome from the gene activity that he would like to modify. He argues that the chromosome *is* Down Syndrome and its perceived value in the production of love and personality, and not the smaller entity of the APP gene and its circulating protein. Strategically, he links the whole third chromosome to the identity of Down Syndrome. In so doing, he invokes and redirects the discourse already in use by parents in their efforts as advocates to secure human and civil rights for their children.

Dr. Mobley punctuates his response with a potent promise, ambivalently stated. He states that with the knowledge accruing around the APP gene and its effects in people with Down Syndrome, the elimination of Alzheimer's Disease in people with Down Syndrome is on the horizon. His caveats ("it's probably over the top, it's probably wrong") will likely be forgotten for those audience members lacking a transcript of the lecture, as they were for me until I transcribed it. At this moment in his lecture, Dr. Mobley leaned heavily on the very familiar theme of curing disease as a project of science and medicine, in this case not Down Syndrome as a disease but Alzheimer's Disease concurrent with Down Syndrome as a disease state described as "almost certain."

LET ‘EM IN

Dr. Mobley closed his lecture at the National Down Syndrome Congress by playing Paul McCartney’s iconic song entitled Let ‘em in. In so doing, he referenced his talk’s beginning where he identified Paul McCartney as a celebrity interested in promoting research related to Down Syndrome. He showed a picture of Paul McCartney and Dr. Mobley in McCartney’s London office, and described him as a new friend to people with Down Syndrome. As a reminder, here are the lyrics to the song:

> Someone’s knockin’ at the door.
> Somebody’s ringin’ the bell.
> Someone’s knockin’ at the door.
> Somebody’s ringin’ the bell.
> Do me a favor,
> Open the door And let ‘em in.
>
> Sister Suzie, Brother John,
> Martin Luther, Phil and Don,
> Brother Michael, Auntie Gin,
> Open the door, and Let ‘em in.
>
> Someone’s knockin’ at the door.
> Somebody’s ringin’ the bell.
> Someone’s knockin’ at the door.
> Somebody’s ringin’ the bell.
>
> Do me a favor,
> Open the door And let ‘em in.
> Paul McCartney, Let ‘em In. Released July 23, 1976

While the exceedingly familiar song played in the background, Dr. Mobley commented “So can you see this is us! This is who we are. I just want to let ‘em in! Paul wants to let ‘em in! […] And you want to let ‘em in to our houses, our homes, our schools, our jobs, and our colleges. Come on! Let ‘em in!”

At this closing juncture, Dr. Mobley wove together the potent cultural symbolism of a popular celebrity musician and would-be philanthropist for the science of Down

Syndrome with the social inclusion that parents and other advocates living under the description of Down Syndrome crave and work so hard to achieve. Punctuating his talk on cognitive improvement through the intervention of medicines for individuals with Down Syndrome, his social justice-oriented demand to let those historically excluded from mainstream society into mainstream society is predicated on his proposed medical treatment of Down Syndrome to more socially acceptable and functional levels, to competence. His commentary is a tacit acknowledgment that the doorway to social inclusion relies on a normality that individuals with Down Syndrome need to acquire for admittance. Furthermore, he argues that they deserve to acquire this normal through the progressive and transformative practices of science and medicine. Throughout his talk, he argued that it is science and its related investigations that will be the knight in shining armor for those living under the description of Down Syndrome, those with the syndrome and their parents.

Dr. Mobley's arguments rest on a disease model of Down Syndrome, with the central presenting feature of Down Syndrome-as-disease a problem of neurological function and cognitive outcomes. Within the scientific world from which he speaks, especially one with a bench-to-the-bedside goal of applied interventions, he is compelled to configure Down Syndrome as a disease for which he is pursuing a kind of cure. Despite the political rhetoric of the national advocacy organizations, and their goals to refute the disease-based language of abnormality, Dr. Mobley's position stands unremarked upon within this scene, suggesting the dynamic contours of a conceptual dichotomy (normal versus abnormal, not-disease versus disease) that refuses to remain still and static in the actual world of practice, politics, and ethical concerns.

The ability to treat something called Down Syndrome has political ramifications, especially with regard to prenatal diagnosis of Down Syndrome. As was described in detail in Chapter Three, prenatal testing and its frequent outcomes of pregnancy termination remains an issue evoking a great deal of concern and a fair amount of sadness for many in the advocacy community for Down Syndrome. Any argument that Down Syndrome can be treated such that people with Down Syndrome will be welcomed in society as they grow serves to stem the perceived tide of unrelenting abortions and it elimination of people with Down Syndrome from our cultural midst.

This remains a very interesting cultural predicament for these advocates. For while they are very concerned that pregnant women do not end fetal life as a result of the genetic anomaly of Down Syndrome, altering the action and interaction of genes once the baby is born and stabilized is hesitantly embraced as progress. Once again, it is the increasing stretch and reach of biomedicalization that enables those with Down Syndrome to live, not only in a physiological sense but within the political sway of argument and rhetoric as well. However, and importantly, the arguments put forth with regard to cognitive enhancement posit that life should be located within the social parameters of normality, revealing again the complex relationship between notions of normality and the concept of being and becoming human.

In this chapter, and through Dr. Mobley's lecture, one can begin to see the contours of complex shifts in authority and expertise. Over the past few decades, and with the advent of deinstitutionalization such that children with Down Syndrome were more likely to be raised at home and in their family worlds, parents became the arbiters of social action and advocacy on their behalf. They worked with clinicians to gain their

own expertise in not only standard medical practice but also were experimenters in alternative technologies. The lecture suggests that science devoted to this historically marginalized population needs parental acceptance in order to move forward. Dr. Mobley needed their acceptance, and eventually he and other researchers will need their children's bodies in clinical trials. However at the same time, it is also revealed that Science (with a capital "S") remains the obligatory passage point for social legitimacy in American culture because of its purported ability to make those who are different, less so and more normal. What remains to be seen is how compelling it may become to embrace science and a disease model for Down Syndrome itself, now that Science has grown interested "under the shadow of dementia" (Katz and Peters 2008).

In her ethnography on amniocentesis, Rayna Rapp called parents – and particularly, potential mothers – who were in the position to choose whether or not to continue their pregnancy following a pre-natal diagnosis of Down Syndrome "moral pioneers" (Rapp 2000). This could be taken further, beyond the pre-natal moment, where living under the description of Down Syndrome can be construed as a nearly constant encounter with ethical concerns. Advocacy in this area, largely organized and enacted by parents, has in recent decades adopted a social model of disability, a stance that views society as pathological and deeply in need of culture change to accommodate diversified needs and abilities.

If we can think of the terrain of the ethical as a space where one contemplates and responds to "the conduct of conduct" (Foucault 1994), considers how one should proceed, the choices one must make, the compulsions to act in certain ways on our own or others' behalf, then this emerging story of cognitive enhancement for people with

Down Syndrome has some complicated dimensions, especially for parents of young children. In parents' hopes for the future, are they willing to enroll their children in clinical trials for a drug the effects of which are not yet known? Are they willing to have their child be in the control group? Are they willing to give up their nutritional supplement, or fulfill other requirements to agree to the clinical trial protocols? Are they willing to "not do" all they can for their kids? All for the sake of research? What are the costs of attempting to "fix" their children? In this instance, what Nikolas Rose termed the "neuro-chemical self" is operative, but very interestingly so, by proxy as parents choose what they think is right for their children. The bio-economic project Rose describes of mining biology for fruitful enterprise seems rather intact here.

In times of perceived community peril through expanding pre-natal testing, Science is holding out a promise of legitimacy-by-disease-model. If an argument that people with Down Syndrome can be treated to cognitively "normal" levels, or even hinted as possible in the near future, the issue of pregnancy termination in the case of a pre-natal diagnosis of Down Syndrome can be refuted much more powerfully. Despite previous disability politics and rhetorics concerning civil and human rights that eschew the disease category and make claims that cognitive disability should not relegate individuals with Down Syndrome to a less-than-human status, encroaching biomedicalization and scientization has the distinct possibility of facilitating a political turn towards disease based advocacy in the arena of Down Syndrome. The multi-decade experimentation of parents reveals that thinking of Down Syndrome as a disease, rather than part of a spectrum of social and genetic diversity, is very compelling. These data

suggest that the work towards becoming human is grounded in normalization, and in this case cognitive normalization through science.

If there is anything that this story reveals, it is that making a space for this kind of difference in the world, the difference attributed to Down Syndrome or cognitive disability in general, is complicated, and increasingly relies on making a mediated and calibrated normal through the intervention of science and medicine. It shows that action by medical and scientific regimes are *perhaps* transformational, but as the classic medicalization concept suggests, completely wound around control, power, and authority at the same time.

MAKING ANOTHER NORMAL

In this chapter, I have outlined the activities of parents and scientists with regard to cognitive enhancement in people with Down Syndrome. I have also noted the uses to which Alzheimer's Disease is put to promote both experimental projects: those of parents with regard to nutritional (and pharmaceutical) supplementation, and those of scientists in promoting their research towards the similar outcomes. In this swirl of activities and actors, the quest for normality in the midst of diversity is discerned, which leads us to question again the cultural meaning behind concepts of normal in contemporary life, especially with regard to either cognition or intellectual ability. For parents and other advocates, this is a predicament associated with their encounter with the ethical as they advocate for inclusion of those they love in a society that often enough remains ambivalent or exclusionary.

In the world of Alzheimer's Disease advocacy, another normal is in the making. This normal emerges through the pathway of self-advocacy and self representation. Notably, a similar pattern has been occurring in Down Syndrome advocacy for some time. This trend is an effort to make public, and involve in advocacy decision-making the opinions and voices of those carrying the diagnosis of Alzheimer's Disease or Down Syndrome. Who gets to represent, and how, is at issue in this emergence of yet another normal that speaks, advocates, and represents. In the world of Alzheimer's Disease, this is made possible through the emergence of diagnostic capabilities that result in a diagnosis of Alzheimer's Disease at purported earlier and earlier stages (and also ages) of the disease. This not only makes more patients, and potential subjects for research. It also makes self-advocacy feasible.

CHAPTER SIX: MAKING VOICE

As we continue to cure cancer, we will have more dementia.
Conversational commentary from a professional advocate.

I wish that I'd spent my time going to more of the early stage presentations. They are so inspirational!
Conversation with a facility administrator, participant at the Alzheimer's Association Dementia Care Conference in 2007

We keep hearing that educational and socio-economic status creates a higher risk for Alzheimer's Disease, but the only people we ever hear about having it are wealthy and brilliant.
Overheard, two nurses talking about a conference presentation centered on the life and death of a man who had Alzheimer's Disease.

In earlier chapters, I outlined the salience of memory and the problem of function in the diagnostic process associated with Alzheimer's Disease. I have also detailed some of the complexities of advocating for individuals with Down Syndrome, revealing the stakes for advocates and the rhetorics of genetics and capability that are deployed in the quest for civil rights and full citizenship. Following a discussion that juxtaposes the advocacy perspectives associated with Down Syndrome and Alzheimer's Disease, I will explore the relatively new phenomenon of making advocates in the arena of Alzheimer's Disease advocacy.

In the situation of Alzheimer's Disease, the ability to prepare a diagnosis at earlier stages of pathology makes more diagnoses and more patients. These individuals can communicate, respond to the diagnosis they have been given, and seek ways to express their concerns and desires for change. Public media campaigns about memory and Alzheimer's Disease contribute to a series of fears and anxieties that propel more people

into clinics to be assessed for memory complaints, sometimes the worried well, and this not only makes more patients but also more subjects for research. As these processes flourish, the representation of Alzheimer's Disease is undergoing a sea change. This chapter takes up questions related to this series of representational realignments.

In the situation of Down Syndrome, processes associated with medicalization and biomedicalization, combined with advocacy, have enabled more and more individuals to live longer lives, thus increasing the numbers of individuals with Down Syndrome living into adulthood and with better prospects for daily lives that are satisfying to them. For some, their lives may include living independently, working, driving a car, getting married, or going to college. As in the case of Alzheimer's Disease, this demographic change has also altered the possibilities for how Down Syndrome can be represented in public.

This chapter's attention on advocacy also emphasizes the extent to which living under the description of either Down Syndrome or Alzheimer's Disease enrolls or includes those closest in kinship proximity to the ones bearing the labels: family members. Historically, both advocacy venues represented the voice of the carers, and their needs for support in their familial encounter with cognitive difference and complex medical needs.

LIVING UNDER THE DESCRIPTION, IN ADVOCACY

I attended the Sacramento Advocacy Day, organized by the Alzheimer's Association, the day after my mother-in-law had died. I felt oddly off-kilter as a fieldworker, not only because I was feeling traumatized by the death of someone I love. I

was also made uniquely aware in the Advocacy Day forum of her having died of an apparently dementing illness. Although she was occasionally described as having Alzheimer's Disease by those working with her in the skilled nursing facility in which she resided, she was multiply diagnosed with vascular disease, Parkinson's Disease or Parkinsonism, and Lewy Body disease. All in all, her situation was one that could be described as a "mixed" dementia with multiple constellations of symptoms and an illness trajectory that most closely matched descriptions of vascular dementia.

I had thought of myself as someone who did not have a familial relationship specific to Alzheimer's Disease. Yet when I bumped into people I knew at the Advocacy Day event, and they asked how I was, I found myself telling them about my mother-in-law, and her death the day previous. This garnered a knowing sort of "Aha!" followed by the comment that it must be especially hard for me to be at Advocacy Day just following her death, said with kindness but surprise as though I should not really be there but simultaneously had special reason to be.

I did not really know what to make of this. I was attending Advocacy Day because it was an important event of my fieldwork. And I was less traumatized by the fact of her dementia than I was exhausted by the total event of death. I was mourning. Yet at the same time, I quickly became aware that talking about her death resulted in a new status for me as an insider to advocacy. It was not merely that other people suddenly viewed me differently, but that I felt differently as a result of speaking about it. That I had been paying attention to my mother-in-law, and her experience with dementia, for many years did not make this new status happen. It was the fact of her death that made that happen, and the story seemed to appear with her death and the conclusion of the

illness state. Now that death had been accomplished, a story emerged and that story shaped me, as the teller, into an insider advocate on Advocacy Day.

In contrast, at advocacy conferences for Down Syndrome I was perpetually an outsider. These events were noteworthy for the friendly conviviality of all who attended. It was easy to chat with anyone, and people were eager to express hospitality and social warmth. I was typically greeted with a tentative, "Are you a parent?" or a somewhat more commanding, "Where is your child?" Seldom have I been assumed to be a parent with regularity, and at first I was startled by the assumption. After telling the inquisitor that I was not a parent, the next question would arrive with great speed, "Oh, so then are you a teacher?" Again, my answer was no. When I explained that I was an anthropologist and a researcher, describing what I was doing at the conference in a sentence or two, my interlocutor often enough smiled quickly, nodded, and exclaimed, "That's great. We need more research." I often had the feeling that they had not listened to my answer at all, except for the word, "research." Our subsequent conversation was often friendly, but typically cut short when another parent caught the conversationalist's eye.

The contrasting and flickering status I noticed in these venues reflect the weighted value in these advocacy worlds of storied experience, and how that might relate to living under the description of either Down Syndrome or Alzheimer's Disease. Without a proper story, and set of relationships, it is difficult to become an insider, at least within the limited time frame of graduate level fieldwork.

In both advocacy scenes, the metaphor of journey (or journeying) was used to describe the relationship between the one who did not carry of label of either Down Syndrome or Alzheimer's Disease, and the one who did. Often, being part of a journey

with the other was regarded in near-spiritual terms, and as a series of important life lessons. For example, a mother told her parenting story publicly and as an introduction to a presentation made by her adult daughter who has Down Syndrome. After expressing her gratitude for belonging to an "amazing" group of people – parents of people with Down Syndrome – she said, "this journey will really show you what you're made of." During an introduction to a panel that included people with Alzheimer's Disease and their spouses, the introducer stated, "We're going to have a panel of people with Alzheimer's disease and a couple of spouses talking about what they've learned through this journey of Alzheimer's disease. We're going to be able to learn from their insight and their wisdom on things that they have picked up after having the diagnosis." Additionally, the use of the journey metaphor in the Alzheimer's Disease advocacy scene often also indicates a journey or passage towards death. This is the language with which people described their relationship to living under the description of either Down Syndrome or Alzheimer's Disease.

Having a proper story as an advocate, and telling it, reflects what Rayna Rapp has called the "public intimacy" of the experience of living under the description of disability. (Rapp and Ginsburg 2001). Drawn into public scrutiny because of the visibility of disability, and compelled into a daily advocacy, a story of family life under the description of disability becomes public. While parenthood is often the portal through which the story unfolds for advocates in the advocacy world of Down Syndrome, advocacy for Alzheimer's Disease is infused with professionals from many sectors as leaders in advocacy. These include scientists, medical clinicians, service professionals (nurses and administrators of facilities), policy professionals, or marketing professionals.

The Alzheimer's Association, unlike Down Syndrome advocacy organizations, is the professionalized place to which family members look for advice and assistance, rather than leading it themselves with a sense of their own expertise and authority.

THE ADVOCACY SCENE

Advocacy leadership and expertise affects the scene of advocacy in multiple ways. The Down Syndrome advocacy conferences at the national level, for example, are fashioned by both the NDSS and the NDSC as family reunions. They include children and adults with Down Syndrome as well as their parent and sibling advocates. Activities include family friendly social events, dinner dances, and talent shows showcasing the performing skills of people with Down Syndrome. New parents bring their infants with Down Syndrome to these conferences, receiving not only sought after advice from other parents but also a fair amount of celebratory attention. Including, and demonstrating, the presence and abilities of children and adults with Down Syndrome are important elements of these conference events, as is an intentional focus on community building (and sustaining) activities:

> Like the performance the night before, the opening ceremonies of the conference felt very much like a festival. Here, it is easy to see and viscerally feel the practice of community in the making. This ceremony began with a folk song entitled "We're on the Upside of Down." There were approximately 50 adults with Down Syndrome representing different regions, as ambassadors to the conference. The ambassadors processed down the center aisle while the "Upside of Down" song was sung. Sung every morning, this song became the conference theme song. The ambassadors were waving, some of them in royal style with slight vertically cupped hands moving side to side in small gestures. Others' waves were big and large. All stood on the stage and the audience stood as they processed, laughing and clapping with the song. Some of the ambassadors were laughing, some were stage struck and gazed back at us.

> After the procession, the ambassadors sat in the first three rows of the audience and stayed through the plenary sessions, which were not designed for the ambassador component of the audience. They went for an hour and a half (a long time to sit). Some ambassadors slept or looked bored. Others sat and stared at the speaker. Future plenary sessions did not include the ambassadors, or a large group of people with Down Syndrome.
>
> Field note: August 24, 2006

An advocate associated with Down Syndrome advocacy asked me during an interview, with mirthful expectation, "Are you hooked on Down Syndrome yet?" This question is possible within a movement oriented towards celebrating Down Syndrome and building community. It is difficult to imagine its corollary, even within the excitement of including individuals with Alzheimer's Disease in the advocacy process: "Are you hooked on Alzheimer's Disease yet?" The political momentum towards more research and a cure, coupled with the professionalization of disease-based advocacy in the United States, makes Alzheimer's Disease and advocacy serious business.

Expert advocacy organized professionally around a disease may include music and procession in some instances, but contrasts with the Down Syndrome gathering. Participants attend these meetings to learn and to network and to act. Organized social events are often sponsored by pharmaceutical companies, and retain a sense of either obligation (as a networking venue) or practical opportunity (a place to get free food). Here is a description of the plenary sessions at the International Conference on Alzheimer's Disease (ICAD) conference in Madrid, Spain, sponsored by the Alzheimer's Association (a scientific research conference):

> I am sitting in the Monday morning plenary sessions. The first speaker just made a joke about how speaking in this venue is like speaking in a venue for a rock star. The plenary ballroom is huge, with seating for probably about 5,500 people. Most people sit in the first third of the room and at least half, if not more, of the chairs are empty. I guess plenaries, spoken

> more simply to communicate to a multi-disciplinary audience, aren't the highest priority for everyone here. As one enters the lecture hall, one is greeted with a vast room filled with simple black chairs, organized in rows. Large screens are hung up over the speakers, and then again about halfway down the hall. Music is played as the participants enter, choose a seat, and wait. The music has a stylized Spanish feel, but is decidedly smoothed out as background sound, white noise. The room has a center aisle, down which people promenade to find their seats. The loud music seems to affect the rhythm of the way people walk and the scene has the feel of a parade that no one in particular is watching. People sit with the people they arrive with, leaving spaces between themselves and those they do not know. People smile and nod to one another politely in quiet greeting sometimes, but the conversation does not extend past the nod or hello, usually stated in English. People continue to arrive as the lectures begin. They flow quietly in and out throughout the talks. This results in a sensation of constant movement throughout the room. It intensifies during the transition moments between lectures. All are wearing their light blue credential nametags about their necks and most are using the conference backpacks.
>
> Field note: July 17, 2006

While the national Down Syndrome advocacy may sponsor one major "family reunion" per year, The Alzheimer's Association regularly sponsors several conferences organized thematically: an annual international scientific conference (held outside of the United States every other year), an annual national advocacy and policy conference, a prevention science conference, and an annual care practices conference. Despite the varied themes, every conference details contemporary science in its quest to cure Alzheimer's Disease. In addition to conferences, the Alzheimer's Association provides services to those living under the description of Alzheimer's Disease, those with the diagnosis and those without. These include 24-hour information and referral hotlines, the Safe Return program (an identification program to accommodate fears that the person with Alzheimer Disease may wander), support groups, and other educational events.

Care versus Cure: Alzheimer's Disease

The Alzheimer's Association sponsors conferences oriented towards caring for those with Alzheimer Disease, as well as conferences oriented towards science and the quest for a cure. It was evident to me that these thematic orientations yielded different constituencies and participation, despite the fact that the conveners and representatives from the Alzheimer's Association remained the same, bridging the two worlds. As a result, each conference had its own look and feel as part of the advocacy scene, although all conferences sponsored by the Alzheimer's Association were thematically coordinated around the color purple, the Association's brand identifying color.

At the Dementia Care conference, laughter and conversation filled the scene, suggesting that people arrived already acquainted with other participants. Clothing was casual, or professional but included lots of fabric. Flowing skirts, blouses, and scarves in brilliant color filled the auditorium with buoyancy and visual surprise. There were round bodies, and large bodies, and curvaceous bodies, primarily of women. What some might call obesity was prevalent, and many – if not most – of the women attendants were in the age category of "middle" age: participants were in their forties, fifties, sixties. While sitting and waiting for the next lecture, I was often greeted by a neighbor and enjoyed our conversation.

In contrast, the scientific and research oriented conferences were decidedly angular. Professional attire – suits – filled the auditorium, and most of the participants seemed decidedly, perhaps pointedly, fit. While a fair number of scientists, clinicians, and pharmaceutical representatives in attendance were women, the room was weighted towards male participants, and ages ranged from early to middle twenties to sixties or so.

The atmosphere was charged with a sense of professionalism and purpose. People did not chat, they networked, scanning the room for the notable or useful. Conversation was short but polite. People moved on quickly, and often hung with either those they knew well or those they were seeking.

It is important to avoid a too-broad generalization. However, the observation that care conferences enrolled professionalized women participants and the cure-oriented science conferences enrolled professionalized men is instructive. The income and cultural capital differential between care professionalization and cure professionalization is wide, with cure professionalization usually garnering the larger incomes.

Notably, those closest in proximity to frontline care and receiving the lowest pay compensation did not typically attend the care conference, nursing assistants or personal care attendants. A panel discussion that included nursing assistants and their perspectives on care was applauded as an innovation to the conference in 2007. Interestingly, this was also the same year that giving voice to people with Alzheimer's Disease was emphasized, suggesting the doubled quality of voice and representation.

Correspondingly, participation at Down Syndrome advocacy conferences was weighted towards women, and mothers. While there were many fathers present who were also were leaders in the movement, the plenary and workshop sessions were lead and attended by mothers of people with Down Syndrome. Various father-only events and workshops suggested that there was an ongoing effort to include fathers in advocacy.

The Advocacy Class

Throughout my fieldwork I felt out-of-class, and indeed, my experience of graduate school itself was one of upward mobility from where I had begun. As I traveled from conference to conference, staying in fancier hotels in expensive cities (albeit negotiated through Priceline.com at much reduced rates), I attempted to fit in and cultivate what seemed often an illusive anthropological rapport in the field. I was aware that while I generally "looked right," I knew that I was walking in worlds of economic and cultural privilege, and this disjuncture contributed to my feeling like an imposter. Certainly it is not surprising to discover that scientific conferences associated with Alzheimer's Disease might cater to the middle and upper middle classes. Most of the participants are clinicians or scientists, both groups enjoying high incomes in American society. That the conferences therefore would cater to the sentiments and values of this professionalized class, priced at a point they (and their respective institutions) can well afford seems reasonable enough. It would be strange to expect otherwise from groups of people who are highly educated and represent the best the United States has to offer its citizens in terms of education, income, and status.

However, I was surprised by the affluence of the advocacy class at the national level.[6] This was as true for advocacy for Down Syndrome as it was for Alzheimer Disease. The filter for status was the national conferences themselves, held in expensive venues with high registration fees. For many in Alzheimer's Disease advocacy, the costs to attend were born by employers, universities, pharmaceutical companies, and the

[6] As noted in Chapter One, there are limits to including advocacy events that are primarily organized at the national level. Further studies in the advocacy associated with local organizations would undoubtedly complicate a story of affluence among the advocacy class.

Alzheimer's Association itself as many in attendance at some conferences were paid staff members from either the local or national offices.

When one considers that entire families attended the national conferences associated with Down Syndrome, then the expense (as well as the commitment) of the participants becomes apparent. As these events were also a locus of fundraising, all dinners and dances required extra payment, and at every turn there was an expectation of donation, either through fundraising auction or ticket pricing. As I met participants, I became aware that some had received some funding support from their local Down Syndrome organizations, and it was easy to understand why this might be necessary.

Both advocacy venues sought recognition in organizing their events. Each Alzheimer's Association conference produced numerous media reports and publicity. Announcements and pronouncements were made about new discoveries in research, with promise for a cure in the future. While conferences devoted to Down Syndrome garnered some media attention, the recognition that seemed most important was the phenomenon of large groups of people and families with Down Syndrome in a fancy and stylish location. I came to interpret the high status visibility of the Down Syndrome conference venues as an insistence upon belonging and normalization, and as a political strategy.

Loneliness

At the Down Syndrome advocacy conferences, it often seems as though everyone is having fun. There is friendliness, laughter, parades, ceremony and ritual, celebratory talent shows and big greetings and hugs all around. This family reunion is joyful in its

outward expression, and fun to witness. I *did* become "hooked" on Down Syndrome. One would guess that there is a strong effort to cultivate this general feeling of conviviality.

But along the way, little bits of interaction creep through the cracks and it seems apparent that not everyone is an insider and not everyone is having fun. And this fact is not simply because they are outsider anthropologists, or professionals without connections. Sometimes, it is the parents who are feeling on the outs, grouchy, concerned about something that distracts them. As parents, they have responsibilities to their child and adult children. One mother disappeared from the conference for a day or two. Her adult daughter was struggling with the crowds of the conference, and with both anxiety and menstrual troubles. The daughter was feeling shy, and pulled back from participating. This struggle pulled on her mother as she tried to support her, and the woman seemed very tired.

I joined another woman for lunch one day, a mother of two young daughters, one with Down Syndrome. She was attending the conference for the first time, and alone. She seemed grateful enough for the company, but quiet. Her profession was nursing; she had cut back her work significantly since becoming a mother of a child with Down Syndrome and now worked only one weekend a month. She seemed regretful about this, both for the loss of income and for the loss of professional prestige.

Her daughter with Down syndrome was ill, and had severe problems with her immune system. The woman was home schooling her daughter because she could not leave the house without getting sick. As we talked, she described a life of extreme social isolation. She could not invite educational and speech therapists into their home to assist her daughter because of the fear of her becoming ill, and developing pneumonia.

The woman seemed very shy and overwhelmed. Many parents do not use the conference as an educational event and instead focus on the social events and local field trips. This woman, however, was seriously attending lectures. Because of the overall situation, she did not imagine ever bringing her daughter to one of these events, nor did she seem to imagine her daughter's health situation ever changing.

I never saw her again at the conference, not at the dinners or dances. I wondered if she was using the time for something else, or if our paths simply never crossed. I looked for her, because I wanted to help her feel welcome. That I felt that urge towards hospitality is interesting, as I could not have effectively integrated her into this community at all given that I was such an outsider. It was a good reminder that not all is as it seems at these conferences. That not all situations of Down Syndrome are full of the joy and goodwill that is often described, that there are difficulties. Some parents have a particularly challenging path to walk, and that they may not always be able to be active in advocacy.

It is evident that advocacy at the level of national conferences draws largely from Americans of European descent and among those who can afford to be there or be sponsored by their employer. The events and their participants reflect cultural values and sentiments associated with status and privilege in the United States. Advocates for Down Syndrome work to create, enhance, alter, and improve existing systems (education, supported work, housing), but within a middle-class sensibility that does not typically align with structural issues in general society. In contrast, the professional organization of the Alzheimer's Association, coupled with its disease-based orientation, has contributed

to their emphasis on ownership. They seek to be in charge of everything, including the development of knowledge, production of capital, and enactment of care with respect to the disease. Renee Beard has coined this the "Alzheimer's Enterprise." (Beard 2005). Fundamentally oriented towards a quest for a cure, but invested in care practices and as a provider of services, the Alzheimer's Association can be thought of as a *total organization*.

ALZHEIMER'S ASSOCIATION AS TOTAL ORGANIZATION

The Alzheimer's Association is a multimillion-dollar enterprise devoted to the disease construct of Alzheimer's Disease. Self-described on its website as the "leading voluntary health organization in Alzheimer's care, support and research," the Alzheimer's Association vision is "a world without Alzheimer's Disease" (Alzheimer's Association 2010). The Alzheimer's Association mission, spanning both care and cure modalities, is to "eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health" (Alzheimer's Association 2010). In June 2009, the Alzheimer's Association recorded in the annual report total assets of $122 million dollars, with an unaudited revenue stream that included all its chapters of $231 million dollars. The Association claims that, since 1982, it has poured $265 million dollars into scientific research devoted to issues of cause, treatment, and prevention (Alzheimer's Association 2009a). As is evident from these economically focused statements, the Alzheimer's Association wields considerable influence through monetary wealth as well

as political presence, and that it is through economic acts that the Association discerns social and political legitimacy.

Borrowing from Erving Goffman's concept of *total institution,* the Alzheimer's Association can be thought of as a *total organization* encompassing disease based advocacy for Alzheimer Disease (Goffman 1961). As a *total organization,* the Alzheimer's Association works towards influencing all the many spheres that impact and respond to Alzheimer's Disease, including scientific research, education, professional care modalities, political advocacy, information and referral, support for those with the diagnosis, support for those who care for people with the diagnosis, and public awareness. To accomplish this, the Alzheimer's Association sponsors scientific conferences oriented to research and cure and clinical and service oriented conferences oriented to care of people living under the description of the disease both patients and their carers, and sponsors policy and advocacy events. On both chapter and national levels, the Alzheimer's Association provides services and competes for state and federal grants to create new ones. The Association is a major private funder of research on Alzheimer's Disease cause and potential treatments.

Through these varied activities, which strategically cover all the issues concerning Alzheimer Disease from a biomedical perspective, the Association has successfully positioned itself – much like the way parents positioned themselves in Down Syndrome advocacy – as an *obligatory passage point* (Callon 1986). Thus, the Alzheimer's Association is a powerful pathway through which many concerned with Alzheimer Disease pass in order to gain public attention and funding for their work or projects. As a service provider, those who live under the description of Alzheimer's Disease as either

patients or carers also encounter the Association and some become either active advocates or participants in the political process.

There is an important distinction between the Alzheimer's Association activities and those of Down Syndrome advocacy. The Alzheimer's Association is strongly positioned within science and medicine, and an important ally and participant in the larger scheme of governance through the National Institutes of Health, and particularly the National Institute on Aging, for which Alzheimer Disease is a primary disease concern. It is a professionalized organization, with an extensive paid staff devoted to political strategy, marketing, and service provision, and enjoys a powerful volunteer staff that includes scientific researchers and high-profile clinicians in addition to people living under the description of Alzheimer's Disease.

In contrast, advocacy devoted to Down Syndrome is organized by parents and families of those with Down Syndrome. While the two major organizations maintain some paid staff, most have entered advocacy through their family connections and as people also living under the description of Down Syndrome. The paid staff I have met fit this description, and live under the description of Down Syndrome as parents. The National Down Syndrome Society and the National Down Syndrome Congress often confer with clinicians and scientific researchers, but do not reside comfortably within the large economic and institutional structures associated with science and medicine. As noted in earlier chapters, there is an ambivalence and historical tension between those who advocate for people with Down Syndrome and the medical/scientific complex of knowledge production.

Strategically, the Alzheimer's Association has become the primary lobbying organization in Washington for disease-specific Alzheimer's Disease funding at the NIH and beyond. It is also the primary political organization attending to care practices for those with dementia-related diseases, under the description of Alzheimer's Disease. However, the interests the Association claims in matters of both care and cure does not mean that resources are allocated equally. Discursively, the most forceful impulse in the Alzheimer's Association activities is to pursue cure and treatment for Alzheimer's Disease. This is a customary emphasis in disease-based advocacy, and it both relies upon and continually reproduces the perspective that Alzheimer's Disease is a pathology that must be eradicated.

One example of a shift from an ethos of support of persons with Alzheimer's Disease to work with science is evidenced in the Alzheimer's Association logo. I was told of this switch on multiple occasions throughout my fieldwork, by both volunteers and paid staff that expressed varying degrees of appreciation or dislike of the change. The logo once was an image of people, with the motto "someone to stand by you." It is no longer in use. The current logo is an abstract set of curves, the first representing the profile of a human head and the second, the shape of a beaker. The new motto is "the compassion to care, the leadership to conquer." The first logo is relational and signifies advocates who live under the description with the one carrying a diagnosis of Alzheimer's Disease. The new logo acknowledges one relationship only: that between the brain, and science.

The Alzheimer's Association becoming a *total organization* is a pragmatic and concerted effort to "own" Alzheimer Disease. The Association is involved in its cure, as

well as its care, albeit in differing ways. It is a service provider as well as an advocacy group. It seeks international as well as domestic recognition on the complex called Alzheimer's Disease. The idea of ownership is born of capitalism and its impact on governance, with a perception that power accrues to the owner of the disease based advocacy practices. By positioning itself as the obligatory passage point, they have done something very similar to what parents as a group have done for Down Syndrome. They have made themselves a powerful portal of influence. There is a difference, however, in that the NDSS and the NDSC do not seek to be total organizations.

WORKING FOR CHANGE: WHAT KIND?

Down Syndrome advocacy, in contrast, works towards culture change in the values and the beliefs held in society about people with Down Syndrome. This is done with a rationale that individuals with Down Syndrome, as well as their family members, deserve not only a caring social attention but also a place in society absent from stigma or prejudice. Whereas the Alzheimer's Association, attentive to disease, identifies the problem as the biological pathology that results in behavioral anomalies associated with Alzheimer Disease, the Down Syndrome advocacy activities locate the primary problem in society. The conundrum of whether it is society or the individual that is pathological is a familiar push and tug in the history of social gerontology (Katz 1996). Concern that life course practices associated with retirement and ageism in society had a causal link to dementia in late life was potent for many in the field and detailed in Chapter Two. However, late life cognitive difficulties have been so thoroughly taken up by medical concerns and disease modeling that this question has largely slipped from view.

The difference in advocacy perspectives is evidenced in advocacy visions and promotions. As noted earlier, the Alzheimer's Association vision is "a world without Alzheimer's Disease," and conference literature contains other taglines, such as "the compassion to care, the leadership to conquer." Compare these metaphors of elimination and battle with this from the NDSS: "to be the national advocate for the value, acceptance and inclusion of people with Down Syndrome" and their vision, "a world in which all people with Down Syndrome have the opportunity to enhance their quality of life, realize their life aspirations, and become valued members of welcoming communities" (NDSS 2010). The NDSC vision is "a world with equal rights and opportunities for people with Down Syndrome" (NDSC 2010).

The distinction arises from Down Syndrome and Alzheimer's Disease respective histories noted in earlier chapters. Problematization that focuses on either individuals (disease pathology) or society (social pathology) shapes the strategies, rhetorics, and tools for working towards the advocacy groups' respective goals, and they are productive in different ways. These choices mark different timelines and different markers of what achievement of advocacy goals might look like. In the case of Alzheimer Disease, the goal of curing the disease places the advocacy movement under the care of the larger economy, politics and investigatory processes of "big" science and medicine. This includes many pharmaceutical companies who work in partnership with the Alzheimer's Association to sponsor conferences and other events. In the case of Down Syndrome, advocacy devoted to culture change spends its energy and its time actively building community through families, despite some interest in scientific advancement (as well) that may help people with Down Syndrome. In the case of Down Syndrome, advocacy is

not emplaced under the care of science, and instead science looks toward the advocacy for help and assistance when they need it. Progress is calibrated along an axis of change in the perceptions of people with Down Syndrome and an expansion of where they are welcomed in general society. It isn't that advocates uniformly employ a social model of disability, but that they work towards changing the social in the first place.

In both cases, conundrums and contradictions arise as each pursues their goals. Each strategy is fully thinkable in American society. Down Syndrome advocacy provides evidence that advocacy does not have to fall in line with standard disease-based strategies even as it exerts an effort to focus explicitly on Down syndrome, rather than the more generalized category of developmental disability.

As was noted in Chapter Four, science and medicine are producing younger patients who are diagnosed at presumed earlier stages of disease. This phenomenon makes possible a representation of the disease called Alzheimer by those who carry the diagnoses, because they are able to communicate and participate with apparent competence. Individuals living under the description of Alzheimer Disease have challenged the Association for more inclusive practices, and the Association has seen their involvement in advocacy as beneficial in many ways. It is out of the social realities of the organization as a total organization, and the Association's dedication to a disease model in the pursuit of advocacy, that this new advocacy emerges.

IDENTIFYING CONSTITUENCIES

Participation in public events by people with Alzheimer's Disease is becoming a vital part of living under its description for a select few. Participants are approached to

participate within the context of a support group experience, and a typical format for presentation is a panel discussion. In these public panels, each person with Alzheimer's Disease is paired with their primary second. In each panel I witnessed, this second person was a spouse, and the marriages themselves were heterosexual marriages. The panels were comprised of people who owned homes, had careers of which they spoke, and despite fears of their financial future had enjoyed an adequate income up to now. The participants range in age from age fifty or so to about seventy-five. In the panels I witnessed, there was no representation from the 80 or above age group, for which the probability for acquiring Alzheimer's Disease is often cited at about 50%. Presumably, there are people in the early stages of Alzheimer's Disease in this group. However, they do not appear represented in these public settings. This may be linked to who tends to participate in support groups, general mobility issues, or institutional issues. These groups are comprised of people living outside of institutional settings. Someone known by the panel participants typically facilitates the public discussion panels, for the facilitator is the support group leader. The support group is itself often allied with the Alzheimer's Association. Themed topics typically include stories of participants' diagnosis experience, daily life with memory loss, and often touch upon fears for the future. They are received with applause and standing ovations, and there is an excitement in the air at then novelty of listening to people with Alzheimer's Disease. The choice of participants in terms of socio-economic status, presentation of self, and race is unsurprisingly parallel to those who attend these events. This is one way to express in the venue of Alzheimer's Disease advocacy, a "just like us" stance.

In 2007, the Alzheimer's Association explored a new form. The Town Hall Forum was lauded as the first-ever national dialogue on Alzheimer's Disease by people with Alzheimer's Disease. It was held in four major metropolitan areas, and I attended the first two in Oakland, CA and in Chicago. Unlike the panel discussions, these forums were structured but unscripted or practiced because registration was open. As noted in Chapter Four, the Alzheimer's Association is interested in capitalizing on the publicity of voice, and these events were quickly noted in local media. The forums were videotaped, and the Alzheimer's Association produced a thematic analysis of what people said (Alzheimer's Association 2008). Additionally, a virtual Town Hall Forum was created through the Alzheimer's Association website. Each of the forums included a moderator; a welcome by representatives from the Association; a short panel discussion that included a doctor, social worker, and person with Alzheimer's Disease; and a speech given by someone with Alzheimer's Disease. The discussion was structured by three themes: interaction with the medical community, changes in daily life, and engaging community resources. The Oakland forum included about 150 people.

At the Oakland Town Forum, Bill Fisher, from the Alzheimer's Association, identified the audience as heroes, asserting that Alzheimer's Disease was a disease to be overcome, and in the work of the Alzheimer's Association:

> Bill Fisher: The Alzheimer's Association is the national movement to defeat Alzheimer's. We are proud to be the largest private funders of Alzheimer's science. We believe that we can create a world without Alzheimer's, and at the same time make a difference in the quality of life for the over 5 million Americans who live with it. […] This program this morning, your presence here today marks progress in the battle to create a world without Alzheimer's, and I thank you for being part of that.
>
> Oakland Town Hall Forum: July 28, 2007

Chuck Jackson, a person with early onset Alzheimer's Disease of the familial type (a genetically inherited and relatively rare form), spoke from the podium and identified the day as a new opportunity:

> We have the opportunity that no one else has had previously as a person with dementia and with Alzheimer's. We have the opportunity today for you to get up and tell people what it is like to have the disease from your side and what it is you need in support services and programs that will help you live better, that will help you with your life. And hopefully in the next few years, I'm going to say in the next few months is what I hope, but hopefully we'll have that cure out there, or at least some good new medications that's going to slow this stuff down so we have a better life with it.
>
> Oakland Town Hall Forum: July 28, 2007

A curious practice emerged as part of the Town Hall Forums. It happened in both that I attended (from my notes):

> When I arrived, a small line had built up at the registration table. I stood behind an elder man who was quite slight. He was with a taller man in his late fifties who resembled him slightly. The second man was graying and balding, slender in body style, and quite possibly the first man's son. They were getting their name badges.
>
> The man in front of me got a name badge with a big purple dot sticker on it. Purple is the ubiquitous color of the Alzheimer's Association. I had been told by one interviewee that this branding had resulted in "legislators know us as the purple people." I wondered if the purple dot meant something (lunch, for example). When I received my name badge, I noticed immediately that mine did not have the purple dot. I almost made a joke comment such as, "hey, why don't I get a purple dot?" when it suddenly occurred to me that the purple dot might mean that the registrant had Alzheimer's Disease. I swallowed the comment that had nearly sprung from my mouth. I suppose it would have been considered in bad taste. Indeed, it turned out to be true. Those with purple dots were people with Alzheimer's Disease, and it was quite visible on the name badge. I wondered what that kind of identification actually meant to those wearing it. Towards the end of the morning, one of the speakers referred to those with Alzheimer's Disease as "the ones with the purple." Here, those with Alzheimer's Disease were quite literally being identified as "the purple people."
>
> Field note: July 28, 2007

This gesture is an indication of the novelty of the moment, thrown as we all were into either a Dr. Seuss-like event filled with star-bellied sneetches, or a scene reminiscent of Jane Elliot's Blue Eyes Brown Eyes classroom discrimination experiment of the 1960's. This was a puzzling practice, as it was not strongly commented upon in the forum. Instead, it was a quiet and largely non-voluntary identification of the participant wearing the name badge as someone living under the description of Alzheimer's Disease. It was a mark that admitted that one does not always know that Alzheimer's Disease is in our midst, and seemed to claim that it was important to know who carried the diagnosis. Unremarked upon publicly, it did not seem to be a badge of honor. Instead, it was an indicator that enveloped the recipients' names and lives in the color of Alzheimer's Disease. I left the forum feeling as though the Alzheimer's Association had not merely branded the disease; it was now branding the people.

At the close of the Oakland event, Hank Greeley, a professor at Stanford and moderator for the event, made this statement:

> I hope you'll continue to be active publicly, politically, and in other ways. I have to say the image of people with Alzheimer's is the person at the end stage of Alzheimer's, the person whose abilities are deeply, deeply eroded.
>
> The people I've heard today are people. They're not a disease. They're not Alzheimer's. They are people who are struggling with the condition or dealing with the condition, coping with the condition, living sometimes happily with a condition. That's very important for the public, for legislators, for others to know. And I don't think that vision exists right now.
>
> Oakland Town Hall Forum: July 28, 2007

This sounded like a pronouncement. Claiming first that this event alters the typical description of Alzheimer's Disease, Greeley notes that the participants in this

room are distinct from this image, full people and competently living their lives. More importantly, he identifies them as a powerful collective that have the ability to change the vision of Alzheimer's, if not the disease pathology. In this pronouncement, he was identifying a new constituency.

There is power attributed to story in these forums, and in advocacy in general. "Telling your story" is a near constant invocation at advocacy meetings where visits are made to legislators (this is done at the state and federal level). The role of narrativized experience is perceived to facilitate change, and in the legislator visits it is hoped that telling stories will lead to increased funding for research. Research is the top priority encouraged by the Alzheimer's Association in the advocacy training associated with legislator visits, although not the only one. Rapp and Ginsburg have noted "public storytelling […] is crucial to expanding what we call the social fund of knowledge about disability" (Rapp and Ginsburg, 2001). It accomplishes a certain kind of cultural work, however shaped it may be through advocacy activities. These forums expand upon the cultural practice of telling one's story as a political gesture, and create a media event around it. They also promise to continue to include the voices that remain competent enough to speak and tell. The inclusion of people with Alzheimer's Disease generated excitement throughout my fieldwork period, and was often discussed in romantic hues. One individual without Alzheimer's Disease, speaking of his involvement with a support group comprised of people with early stage Alzheimer's Disease, stated publicly, "I almost felt like it was unfair that I didn't have the qualifications to be a member of the group. At the time I didn't understand exactly what were the characteristics and the circumstances that were generating this kind of communion, but I knew that it was

healing." However, identifying new constituencies also opens up other horizons of influence that may, if the commitment holds, alter not only the face of Alzheimer's Disease, but also its relation to the concept of disease.

The effort to separate themselves from aging old bodies with dementia is apparent in the voices of the new face of Alzheimer's Disease as they speak and act on their own behalf. Following a workshop session at the Chicago Dementia Care 2007 conference detailing strategies for including the voices of people with early onset Alzheimer's Disease in public, a participant stood up and spoke (from my notes):

> She was sitting in about the fifth row and she held in her hand a piece of paper upon which she had been making notes. Her voice was dynamic and she projected it loudly without the use of a microphone. As she spoke, she turned dramatically to make eye contact with both the speaker panel and the audience. She was focused and energetic.
>
> She said that she had a diagnosis of early onset Alzheimer's Disease. She looked to be in her late forties or early fifties. She said that she felt that a comment made during the presentation that early onset and late onset Alzheimer's Disease was the same disease was erroneous. She said that early onset people with AD often had other symptoms. They had Parkinsonism, psychological issues, balance issues, vertigo, emotional issues that she claimed people with late life memory loss and Alzheimer's Disease did not have. She said that people with early onset Alzheimer's Disease fall a lot. She said that it was not right to say that they were the same disease when it was quite possible that they were not because of these differences in clinical manifestation. She also said that because they were different diseases, they also possibly should have different diagnoses.
>
> She said that she works with her clinician. "We don't do Aricept," she said, "but we do a combination of western medications and eastern medications. The woman sitting beside me nodded. She said, "and I have seen improvement and reversible AD." She pointed to a woman seated at the end of her row of seats. "My sister," she emphasized, "was so ill that she could barely move and she could not talk. But look at her now. She is here, and she is dressed very appropriately, very fashionably, she is able." The woman she pointed to looked in a focused way towards the front of the room where the speakers stood. "I am on the board of my local Chapter of the Alzheimer's Association. I am the secretary and I take good

> notes! But I think that it is important for me to comment on this, because we really should not be saying that these two situations are the same."
>
> The speakers thanked her profusely and loudly. "Thank you so much for speaking out!" they said. The audience clapped loudly for her in response.
>
> Field note: August 28, 2007

One can detect in her argument a resonance with the experimentation in alternative treatments by parents of children and adults with Down Syndrome, and the cultivation of expertise and improvement despite medical paradigms. Instead of eschewing a disease model, she suggests a new disease state that distinguishes her and her sister from late onset Alzheimer's Disease. She does this, in part, by addressing her understanding of symptom differences, but relies on the apparent competence of her sister to prove the point.

Additionally, participants in the Town Hall Forums sometimes challenge the standpoint of the Alzheimer's Association, and this suggests an emerging disability consciousness:

> I live in the Chicago area and I live in the suburbs, and there are very little for early-stage support groups. There's a few, but considering the size of this community and all the suburbs, it's woefully inadequate. And I have asked the Alzheimer's Association and there's just not much help there. So I'm asking to please address this. It sounds like now there's an early-stage focus in the Alzheimer's Association. Please, please address support for the people with this disease. This is the only disease I know of that has almost nothing for the person with the disease, all kinds of things for the [cure of it]. Thank you.
>
> Female Participant, Chicago Town Hall Forum: August 27, 2007

> My doctors assured me that I was in the very early stages of this disease. For a while, I would be able to continue to do my job. But I needed to convince the mayor and city council that I was still able to carry a weapon and protect the citizens of Lexington.
>
> I met with them, explained what the doctors had told me. They assured me they had faith in me and my doctors to know when it was time for me to

> retire. I admire and respect them for their courage and continuing support. […]
>
> This does affect the elderly, but more and more young people are being diagnosed daily. So after several family meetings, we decided to go public with this very private part of our lives. We knew there would be risks. We knew [there would be those] who disagreed with my decision to continue working, but I felt it necessary to let the citizens of Lexington hear these words from me.
>
> Chicago Forum, Formal speaker Spencer Johanson, who drew much media attention for continuing to work with a diagnosis of Alzheimer's Disease. He is a police officer and continues to carry a gun.
>
> Chicago Town Hall Forum: August 27, 2007

> The immediate message out of the support group was, "Well you should stop driving. You should stop driving immediately because there's just all this liability involved and what if, what if." And my answer to that is if I had anything else you would be looking for a way to enable me. If I had anything else, if I couldn't drive you would be looking for a way for me to get around. And I should let my capabilities drive my activities. A center offers a very intensive driving-evaluation program. So I paid for it out-of-pocket. I went through the driving evaluation. It's actually a three-hour test. It's very difficult. And I actually got a perfect score. I was pretty pleased.
>
> Male Participant, Chicago Town Hall Forum: August 27, 2007

These challenges to assumptions about Alzheimer's Disease (that there should be a priority placed on care, that people can continue to work and drive) indicate possibilities for the emergence, over time, of a political disability consciousness around Alzheimer's Disease. Taken further, this may shift the priorities of the Alzheimer's Association, should Alzheimer's Disease continue on its trajectory towards a construction of chronic disease that is lived with for many years.

These kinds of priorities have caused one Alzheimer's Association staff member I spoke with to muse over whether the "vision of a world without Alzheimer's Disease" is still appropriate, claiming that he has been asked by individuals with Alzheimer's

Disease if that means a world without them. While this may a heartening thing to consider, it is telling that the thought was thinkable only when the new representation was made possible by early stage and early age diagnosis. When it was primarily a disease of the aged, making Alzheimer's Disease go away was the primary aim.

CHAPTER SEVEN: CONCLUSIONS

In this dissertation, I crafted arguments through two narratives. In the first, I told a story of the emergence of cognitive enhancement for individuals with Down Syndrome, a relatively new endeavor for scientific study. This urge to investigate and improve cognition for people with Down Syndrome is growing from within research on Alzheimer's Disease, and depends upon the development of a new pharmaceutical product. It is derived from genetic study of pathways leading to the hallmark characteristics of Alzheimer Disease: plaques and tangles in the brain. I explored this interesting development as a predicament of expertise and ethical choice around cognition and its alteration. Parents have developed their own expertise over the past four decades and in the shadows of societal neglect of individuals with Down Syndrome. Their expertise includes enacting practices located outside standard medical recommendations. This expertise is queried as science grows interested and invokes its own powerful production of knowledge. The politics of persuasion, as well as the ethical conundrums experienced by parents caring for young and adult children with Down Syndrome demonstrates that advocacy in an arena that has previously eschewed a language of disease may begin adopting one in order to pursue their goals of societal acceptance. In this story, I argue that societal acceptance turns on the concept of normal, coupled with the achievement of competence. Importantly, drawn into this narrative are not only issues pertaining to aging and Alzheimer's Disease, but also the unique pressure that prenatal testing and abortion bring to bear on the lives of those living under the description of Down Syndrome.

In the second narrative, I discussed the activities of medicine, science, and advocacy in the arena of Alzheimer Disease. Diagnosed with Alzheimer Disease and other dementias at earlier stages and ages of disease have led to not only the creation of more patients and more subjects for research, but also new and intriguing representations of the disease itself. People now represent themselves as having Alzheimer Disease, and certain among these individuals have become a part of the advocacy movement associated with it. In public, representations of the disease are shifting from the unknowable and unrecognizable dementia patient who babbles and acts anomalously to individuals who carry the diagnosis but nonetheless present themselves to others as competent and socially privileged. This, too, however, depends upon the concept of normal in order to be enacted. Those whose abilities stretch these boundaries quickly find themselves unable to participate or understand their surrounds. I argue that with the new fascination towards early stage people carrying the diagnosis, people undergoing the more advanced stages of dementia are potentially pushed to the periphery of advocacy's concerns.

A thread running through these two primary narratives is the urge toward ideals of normal competence. This urge is facilitated by the movement of science and medicine, and relies upon the notions of disease and cure. In both arenas, a new body is being sought and made, resulting in a new Down Syndrome and a new Alzheimer's Disease. The new Down Syndrome results from the striving to enhance, and the new Alzheimer's Disease from an effort to label (and potentially treat) earlier in the life course. The latter course is not to enhance, but to preserve what remains. The consequences of these efforts include the possibility that those who are less functional, less flexible, and less able to be

in public in a way that is recognizable as normal enough will remain invisible, in a manner much like the invisibility enacted through the older diagnostic category of senile dementia.

COMPETENCE AND GOVERNANCE

In the public conversation surrounding pre-natal testing recommendations, advocates concerned with Down Syndrome often consider these new standards to be informed by eugenics, with the potential of genocide. Similarly, although perhaps more quietly, anxieties about euthanasia often reference Alzheimer's Disease (from both sides of the argument). However, a critique calling upon eugenics is worth thinking through carefully.

In Matthew Thomson's explication of the legislative and social realities in the early twentieth century United Kingdom regarding cognitive disabilities, he deviates significantly from a typical argument noting eugenics, or eugenics thinking, as social cause for problematic practices. Instead, Thomson argues that the complexity of the cultural response had much more to do with processes associated with a burgeoning democracy instead of the outright exclusion associated with eugenic practice. In a country that was evolving democratic practices, enfranchisement increasingly depended upon notions of citizen competence, with the effect of throwing competence and capacity in high relief and cultivating public concern and attention for those who did not seem to pass muster. This resulted in demarcating who could participate, when, and where they might participate in the new order. Prior to democracy, the question of who might

participate in the fate of the nation was, for better or worse, not a fraught question (Thomson 1998.)

It would be a mistake to transfer Thomson's argument wholesale to the United States context, as both eugenics and democratizing processes followed differing trajectories. However, his questioning of the sheer force of eugenics is quite useful for the critique that it offers. Additionally, if his argument is taken seriously – and I think it should be – then it calls for a questioning of the relationship between cognitive disability, social practices related to the care of those with cognitive disabilities, and democracy as it has been crafted in the United States.

In the preceding chapters, the social construction of cognitive disability has been explored through the dual lenses of Alzheimer Disease and Down Syndrome, as well as where they have become interestingly conjoined in scientific research. The assemblage of practices and systems associated with the care for those who need assistance and support, as well as the pursuit of a cure for those situations considered to be a disease problem have been described largely through public advocacy, an advocacy that has either been managed through carers (parents, in the case of Down Syndrome) or professionals (in the case of Alzheimer's Disease.) Data from this study suggests that cognitive disability, regardless of cause, is problematized through the dilemmas of competence. If this cultural value is a feature of democracy, as Thomson suggests, then it is likely to remain an enduring trouble in the ethics and politics of caring and/or curing either Alzheimer's Disease or Down Syndrome.

As has been demonstrated, pharmaceutical products have been and are being developed for both Down Syndrome and Alzheimer's Disease in pursuit of physiologic

correction that can be understood as cure. Nikolas Rose has noted that pharmaceutical means are key to governance of populations and individuals in the contemporary (see Chapter Two), and also part of assemblages of science, medicine and economies that now regard molecular processes previously "devalued as pathology" to be opportunities for commodity production and economic growth (Rose 2003b). Certainly, these machines are at work in the situations of Down Syndrome and Alzheimer's Disease.

However, in both arenas correction or cure is not yet accomplished through pharmaceuticals, but held out as a promise of Science requiring much capital and personal investment. It is in the extension of the promise, and through the rhetorics of persuasion, that the entanglements of bodies, lives, science, and medicine make visible the contours of normal and competence in everyday life. It must not be forgotten that in order to proceed, science and medicine need that which they have contributed to making: the bodies of consenting and able people who can speak of their experiences in a clinical trial, extending research. Likewise, the attraction of Down Syndrome as a potentially "bioavailable" model for Alzheimer's Disease study garners persuasive rhetorics concerned with correction to normal and competence levels (Cohen 2007). Contrary to what Rose has proposed, the scene of cognitive disability or disarray is not characterized by "variation without a norm," or "anomaly without abnormality" (Rose 2003b). Instead, normal and competence are depended upon to formulate rationales for action. The tenacity of these concepts in calibrating societal acceptance and accommodation turn on historically inflected notions of human status. And it is the anxiety associated with becoming human and maintaining human status that provokes the ubiquitous question, "Is it Alzheimer's?"

At the moment, living under the descriptions of Down Syndrome or Alzheimer's Disease with relatively high levels of competence is not the majority experience. Governance of those I have come to call *recalcitrant bodies*, bodies and people unable to access a normal or competent representation of self and who may act in unpredictable ways, requires at least a second body, a second person (Cohen 1999, 2006, 2008; Edgerton 1993). In the preceding chapters, I have described the enrollment of these second bodies, usually family members, into advocacy venues seeking mutual aid and opportunities to participate in politics on their own and their family member's behalf. Insight into how that second body is enrolled came for me in the form of my own family care situation.

Caring for Janice

When I grew concerned about my mother's cognitive status, I called on Adult Protective Services in her part of the country. Through that call, she received attention from social services (which she did not like and ultimately refused) and some limited services were enacted to assist her in what were thought to be her key deficiencies. However, as part of the process, my brother and I were first asked, and then strongly encouraged, to initiate power of attorney authorities so that in the event of further emergency we would be authorized to act on her behalf. Indeed, this was the first question the social worker asked me, "Are you willing to serve as power of attorney for your mother?" After some thought, the answer was yes, and both my brother and I worked diligently to get our mother's permission and signature on forms that would give us this authority under certain conditions to act.

A few months later, when things seemed horribly awry, I called Adult Protective Services again, and I spoke with the social services person who had worked with us previously. In this second conversation, I was rebuffed. Her first question was, "As power of attorney, what are you going to do about it?" What this made clear to me was that in the first instance, the primary goal of the governmental support system associated with Adult Protective Services was to enroll the family as authority. Once that was done, the responsibility had been successfully deferred away from the state. In the second instance, instead of assisting me, they were able to toss the issue right back at me as power of attorney. That one still might need the services of Adult Protective Services even if one had power of attorney seemed to be beside the point. The catch was that the power of attorney did not enable me to force my mother to do anything at all. In successfully getting us to get our mother's signature to act on her behalf, the state had deferred responsibility to those thought more appropriate to deal with problems from the perspective of a cash strapped and overworked system: the informal care circle of family.

What this elides is the fact that someone can be competent enough legally to avoid enacting the authorities associated with power of attorney, but can still be a danger to one's self and others. The issue becomes what kind of danger and who should take care of it, a matter of risk. In effect, I was told by the social worker that now that I had power of attorney the matter was no longer a matter of state but mine alone. Furthermore, it was my job to figure out what came next; the care that existed for me as the responsible person was in the form of commiseration and listening, but not material or concrete. Given that key services and resources were accessible free of charge through Adult Protective Services, when the gate was closed by this agency it placed the economics of

my mother's situation at my feet as well. It is in this context, responsibility with little governmental or bureaucratic systems efficacy, that people who can turn towards advocacy venues. Governance of the recalcitrant bodies of old age is actually the governance of younger or more competent associates. This experience taught me in a profoundly personal way that I was the person being governed and managed because my mother was becoming precariously ungovernable. She had escaped governance, and in her escape was weaving her way into my world.

Over time, I came to understand that it was precisely the responsibility that lacked avenues of assistance that was, in fact, the difficulty or burden of care. It was constructed through the avoidance of state. Perhaps excitement over the new representation of Alzheimer's Disease reflects this reality best: the new voices can speak to the ones most surveiled in the landscape for the responsibilities to care informally and the inspiration that ensues obfuscates the burden of state avoidance.

CARE AND/OR CURE ADVOCACY

As demonstrated in previous chapters, living under the description of Down Syndrome has cultivated an advocacy devoted to making a space for individuals with Down Syndrome in our midst, and in society. This advocacy effort spans the entire life course of someone with Down Syndrome, from advocating for efficacious and attentive medical care in youth, to promoting inclusive education that now in some cases extends past high school and into college life, to crafting job opportunities and supportive work practices. This cultural work responds to the historical stigmas experienced by people with Down Syndrome and their associates, addressing inequities and stigmas head on. In

working towards culture change, these advocates pursue not simply an advocacy of care, but also work to create a community of care organized around the metaphor of family.

In contrast, the needs of carers catalyzed the Alzheimer's Association, but their project was quickly co-opted by the NIH and the powerful movements of medicine, science, and professional disease based advocacy (Fox 1987, 1989). Although this integration and collaboration with science and medicine facilitate the movement's power, it also limits it to marketing strategies and a primary orientation towards cure. The advocacy movement plays a strong supporting role in promoting, funding, and publicizing research activities. It seldom questions them or the stigma and troubles received by their core constituency. As a result, culture change is not a consideration. Instead, cultural forms are taken up and utilized to gather more momentum and more capital in pursuit of the goal of cure. In a health economy devoted to disease markets, this capitalization of pathology is necessarily competitive and grounded in marketing strategies for recognition.

The cultural resources most drawn upon in cultivating public angst and terror with regard to Alzheimer's Disease are negative associations with growing older. Folding the former senile dementia into the rubric of Alzheimer's Disease situated the demographic problem of the disease within the context of old age, fomenting what one critic has called an "apocalyptic demography" (Robertson 1999). A commonly repeated metaphor for the demography associated with Alzheimer's Disease today is that it is a "silver [or grey] tsunami" located frighteningly on the horizon and demanding emergency attention. The first time I heard this metaphor was at a small legislative hearing in Sacramento expressing the need for state-specific planning to address Alzheimer's Disease, however

it is now used regularly in public media, and I have heard its use in both the United States and the United Kingdom. The strategic use of a metaphor signifying so-called natural destruction defers blame and culpability for the disease, but the use of adjectives associated with age ("grey" or "silver") identifies debilities associated with aging as threatening to the survival of all.

In earlier chapters I discussed the ways in which foregrounding early age and early stage people with Alzheimer's Disease avoids the public problem of ageism in representing the disease. The new representation is lauded for its ability to communicate the idea that people with Alzheimer's Disease are *just like us*. However, the emphasis on those considered too young for Alzheimer's Disease continues to point to the old person with advanced dementia as the terrifying endpoint of Alzheimer's Disease, the ultimate other. The reliance upon sentiments and fears related to old age are the subtle anchoring point in the Alzheimer's Association marketing strategies. It is for this reason that this disease-based advocacy movement cannot contemplate culture change in the same way that advocacy devoted to Down Syndrome does. The Alzheimer's Association relies overmuch on the stigmas one might wish they would counter.

The "Alzheimer's Enterprise," as a total organization is locked in to a system of alliances grounded in its first assumptive proposition: that Alzheimer's is a disease. It may very well be, and it is not the purpose of this critique to prove otherwise. Instead, I want to reiterate that age has been problematized and enveloped in medicalization to such a great extent that it has become difficult to think outside of the medical in pursuit of change or resolution (Estes 1989; Kaufman 2004). However, the challenge that evidence from advocacy for Down Syndrome poses is that it is plausible to think beyond the

disease concept, work towards culture change with regard to attitudes about age, and strive to enact caring practices encompassing not only the person who carries the diagnosis, but those living under the description with him or her as well. The logic of pursuing a cure is taken for granted, for with a cure the dilemmas of care are removed. However, the promissory note of science in the arena of Alzheimer's Disease has been with us for some time without securing a cure despite the infusion of much money, participation, and attention. In the meantime, the mixed dementias of old age persist and the people encountering them are in need of care. Indeed, any cure that might be uncovered will only serve the present-day young (or younger), a fact tacitly acknowledged in its current representation.

CONTROL AND TRANSFORMATION

The arguments and stories presented in this dissertation leaned on control or transformation, noted through the concepts *medicalization* and *biomedicalizaton*. Control of populations and individuals was demonstrated through the reliance on the concepts of normal and competence to enact human status and social worth. This presents dilemmas for those unable to perform or present themselves as competent and their carers. Control is also evident in the activities of governance and the assignment of responsibility for those who are less able. Transformative possibilities include new biosocial identities through advocacy, emerging representational politics only recently made available through diagnostic and other practices, and the possibility of a new experience of either Down Syndrome or Alzheimer's Disease. These transformations empower science and medicine to act through research, creating more potential subjects to enroll in study and

investigation. Both control and transformation are made plausible within the medical and scientific gaze, and its powerful legitimizing effects in a scientist society.

Additionally, control and transformation are implicated in the cultivation of neurodiversity in public. The ongoing effort to calibrate cognition, through functional or memory measurements, makes new identification of persons along a spectrum of ability that then become available for potential treatment. The earlier form of surveillance, the intelligence test (IQ), has been transformed with wider reach to potentially an entire citizenry. If the speculations of one clinician become actual, that testing for Alzheimer's Disease will eventually begin in pediatric clinics some day, then an entire life course will become subject to risk assessment and management for what has been understood for the past thirty years to be a disease of late life cognitive decline. It might also result in newer whole-life models for Alzheimer's Disease, akin to the way that science now regards the bodies of people with Down Syndrome as a model for Alzheimer's Disease.

In the confluence of control and transformation, novel ethical dilemmas emerge. The distinction between them is decidedly muddled, for both exist simultaneously within each gesture towards progress. Each attempt to control cultivates resistance and the potential for transformation. Each transformation holds within it a commitment, and a limit. This is, ultimately, our situation of the contemporary: that we act from an ethical stance without the ability to discern all the possible consequences.

Those who make decisions in the arena of cognitive disability or disarray are rarely those who carry the label. The "capitalization of vitality" passes through obligatory passage points that render decisions in accordance to their perceptions of their problems (Rose 2003b). In the case of Down Syndrome, parents will decide the extent to which

their children will be subject to investigation, and the limits they will permit in their own efforts to care. It is parents who will decide what kind of self, person, or personality they will participate in fashioning in their child, largely without knowing the full consequences. They will do so under the pressures of a society that routinely practices rejection rather than acceptance, and they will do so with a faith and hope that tomorrow may be a different kind of day for their children. People encounter ethical dilemmas every day. They reach for what is at hand to fashion arguments that contribute productively to their plans, projects, and strategies.

If there is a caution in these stories for the Down Syndrome advocacy movement, it is to proceed carefully in the potential turn towards disease-based advocacy. Alzheimer's Disease and its related advocacy movement reveal the road-not-yet-taken for Down Syndrome advocacy. Located within the engines of the medical industrial complex, the contours of the power of Alzheimer's Disease advocacy also reveal its limits. It seems to me that a world that can maintain an ambivalent and critical stance to disease might be able to include more of its participants, altering our collective –isms and biases as we move forward.

In this dissertation, I have pushed toward an anthropology of senility, paying attention to "what senility might be becoming" (Cohen 1998; 2006). Indeed, this remains an open question.

As we have seen, for those living under the description of Down Syndrome an anthropology of senility is increasingly becoming possible through the life enhancing and extension practices of clinical medicine, science, and a changing societal reality for those with Down Syndrome. Now subject to the more mainstream terrors of Alzheimer's

Disease, Down Syndrome may appear less different from the rest of us than it used to be. The transformation associated with enabling and extending life has its shadow and, as we have seen, fear of Alzheimer's Disease can be utilized efficiently towards an evolving science now interested in enhancement and alteration through pharmaceutical means.

In the scene of Alzheimer's Disease, senility is also being re-fashioned and re-packaged. No longer simply a plight of the old-old, marking age through diagnostic practices associated with memory and Alzheimer's Disease occurs at earlier ages for many. Normal aging, the number one risk factor ubiquitously heralded at all points for Alzheimer's Disease, is the first tick off the marking system. Fascination with the transformed possibilities for self-representation in Alzheimer's Disease, the realities of the old-old slip from view, yet remain in plain sight and subject to the vast industries and fragmented systems built to manage old age debilities. In an effort to avoid negative stereotypes with advanced age, the new Alzheimer's Disease is heralded as an advocacy progress, and a literal embodiment of the advances made and promised by science and medicine.

EPILOGUE

Trying to reach through the fractured sentences was like reaching into a briar patch, but there were no apparent scratches. My mother did not have the insight to realize that she was stumbling, and I found the interactional challenge interesting. The phone conversation came after a month's silence. I had been calling her cell phone daily, but the phone went unanswered. I kept in touch by talking to those around her - the aides, administrators, and public health nurse associated with the assisted living facility where she resides.

My mother was stumbling verbally, but it was clear she was in a decent mood, which gratified me. The once-habitual emotional storms were sometimes present, but lately she seemed pleasantly comforted by my voice over the phone. After decades of heartache and strain between us, this was a welcome respite. I was happy too, happy that I was able to listen to her and enjoy the conversation. It reminded me of when I was small, and when she enjoyed my company.

At the end of her life, I have become one of my mother's best friends and advocates. This could hardly have been predicted, and I am grateful to have the ability to respond to the challenge of caring for her. I am aware that dementia is facilitating the truce, and my own sense of peace. While much could be made of the legal, political, and cultural construction of vulnerability in elder adults, this new vulnerability in her is softer, local, and gently leading us towards the death of our while-alive relationship.

It seems to me that much has been made of suffering with regard to cognitive change and decline. It is easy to understand ethical commitments in a scientist cultural

scene to pursue lines of inquiry that might release the sick from perceived suffering, to *cure*. There are few narratives of the social healing resultant from illness, dementia in particular. Arguably, the social healing arrives through *care*. The disease concept focuses our attention on the deficits, the declines, and the social traumas. And yet without dementia, I would not be in my mother's life. She would not have let me in, and perhaps I would not have tried.

I reach out to her with my language, by phone, and with my presence during my visits to her. I scheme up things that I know she would have liked. I do not know how much satisfaction she gets from these activities now: watching Bette Davis films, receiving biographies of celebrities, catching up on the lives of family members. But I do think that she finds satisfaction in the gift exchange, and in the surprise of kindness.

My mother has led a life full of color and drama and catastrophe and loss. Much of this she appears to have made through her own actions, responding as she did to the whims and caprices of impulse, desire, compulsion, and addiction. She has seldom had a moment's rest or peace, as far as most outsiders could tell.

Recently, I dreamed that she was happy and chortling, safely enveloped in the arms of a loving god. She had no fear, and she was smiling. If dementia gave her that, and gave me this, I will settle.

All's well that end's well.

ADDENDUM ONE: MULTI-SITED ETHNOGRAPHY

In recent decades, ethnography as a practice of inquiry and as a writing genre has been subject to much critique and experimentation. Central to these debates is a doubled angst concerned with a profound doubt that a localized method can address concerns of wider import in a globalized world, and the politics of representation and authorial power in the writing of ethnography itself. As a result, many scholars involved in the debate have suggested new languages and analytic lenses for understanding and describing the complexity of contemporary human social forms (Appadurai 1996, Rabinow 2003). Additionally, the ethnographic method has itself come under scrutiny, with recommendations for revision.

George Marcus is perhaps the most visible theorist of multi-sited inquiry in anthropology (Marcus 1998). In his formulation, multi-sited ethnography emerges from the effort to track a cultural formation "across and within multiple sites of activity," an approach that favors circulation over stasis and connections over separations. Marcus describes this methodological orientation as a revival of comparative work in anthropology through "juxtapositions of phenomena that conventionally have appeared to be (or conceptually been kept) 'worlds apart'" (Marcus 1998:86). He notes that the ethnographer is both engaged in inquiry at the same time that she is involved in constructing aspects of that inquiry through the selection of field sites and the formation of arguments as to the relations between them. This reflexive relationship of the ethnographer within her ethnographic work is more nuanced than other accounts of reflexivity that emphasize personal aspects of the ethnographer's life vis-à-vis the life of

her "informants," often positioned with less power and status (see Behar 1993 as an example).

Marcus utilizes a metaphor of "following" in describing how multi-sited ethnography might be conducted. He argues: "Follow the people," "follow the thing, "follow the metaphor," "follow the plot" (Marcus 1998:90-95). This method reflects "anthropology on the move" and requires a new emphasis in flexible research design. Methodologically, one can no longer simply identify an exotic or interesting place to go, but one is compelled to draw together places, people, and events oriented around an object of study and its related questions. Notably, an analysis of this sort cannot make a claim to holism, a once treasured aspect of the culture concept in anthropology, but necessarily relies upon partiality, flexibility, and uncertainty.

The observation that the ethnographer is the primary "tool" in ethnographic research is commonplace in texts regarding anthropological methods (see Bernard 2002, LeCompte and Schensul 1999). In a multi-sited ethnographic research design, not only is the ethnographer a "tool," but the sites themselves are, too. Through the constructive quality of anthropological research design and inquiry, these fluid sites-as-tools are the "right tools for the job," organized through a doable problem located in a complex world (Clarke and Fujimura 1992).

Multi-sited ethnographic research projects are complicated to organize and inherently improvisational. The methodology requires flexibility and movement, either practically (moving from place to place) or conceptually (moving between different levels of analysis). Multi-sited ethnography has been proposed as one way to conduct ethnographic research in situations where the influences on day-to-day life are enacted

from distant and widely dispersed locales. This method was chosen for this project because it is especially adept at unpacking advocacy and policy initiatives and their corresponding outcomes and effects.

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