

CULTURAL CONTEXTS OF HEALTH AND ILLNESS
AMONG THE LANCASTER AMISH

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ABSTRACT

Martha King: Cultural Contexts of Health and Illness Among the Lancaster Amish
(Under the direction of Dorothy Holland)

This work uses anthropological approaches to navigate and elucidate the cultural dynamics of the Lancaster Amish. Group identity and cultural practice are understood here as the driving forces behind Amish negotiations with technology. Using healthcare as a lens for understanding this dynamic, this dissertation delineates a pluralistic healthcare system utilized by Amish church districts in the Lancaster, PA area. One part of that system—biomedicine—is further elaborated through discussion about Amish cooperation with a cutting-edge genetic treatment/research facility, the Clinic for Special Children (CSC).

This research was motivated by two broad questions. How do Lancaster Amish districts shape their use of medical and other technologies? And how does CSC create a biomedical environment where this kind of cultural negotiation can occur? A number of conceptual frameworks are put into play here: identity and action in cultural worlds; medical pluralism and health technologies; and processes of embodiment. This dissertation describes ways in which the Amish “body” mediates the self and the community, intercedes for that community with the outside, and builds the artifacts that populate their cultural worlds. Those bodies are deeply imbedded in what it means to be Amish—from the twisting double helix of a Lancaster Amish genotype to the daily implications of living in closed religious communities. Using qualitative methods, this dissertation adds vital richness to medical anthropology and Amish studies while providing an excellent case for understanding challenges occurring in translational medicine.

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List of Abbreviations

CHOP	Children’s Hospital of Pennsylvania
CNM	Certified Nurse Midwife
CSC	Clinic for Special Children
GA1	Gluteric Aciduria Type 1, also known as glutaryl-CoA dehydrogenase deficiency
GCDH	Glutaryl-CoA Dehydrogenase, a gene with the cytogenetic location 19p13.2
OMIM	<i>Online Mendelian Inheritance in Man</i>
MIM	<i>Mendelian Inheritance in Man</i>
MSUD	Maple Syrup Urine Disease
SNP	Single Nucleotide Polymorphism

Translations of Frequently Used Words

<u>PA German</u>	<u>English</u>
<i>Abstellung</i>	putting away, placing off limits
<i>Brauche</i>	powwowing; traditional PA Dutch folk healing with magical elements
<i>Die Botschaft</i>	literally, “the message;” an Amish correspondence newspaper
<i>Gelassenheit</i>	equanimity, conquest of selfishness, yielding
<i>Gmay</i>	church district, community of practice
<i>Meidung</i>	social shunning, “the ban”
<i>Ordnung</i>	community rules of order
<i>Rumspringa</i>	running around
<i>Uffgeva</i>	giving up

Chapter 1: A Study of Practice in Lancaster Amish Communities

Elements of Amish society both attract and confound outsiders— their fundamental religiosity, the confusing nature of their temporality, the appearance of contradictions in their way of life. This work uses anthropological approaches to navigate and elucidate the cultural dynamics of the Lancaster Amish. Several conceptual frameworks offer useful approaches for parsing Amish society: identity and action in cultural worlds; medical pluralism and health technologies; and processes of embodiment. As one of the few socio-cultural explorations into Amish constructions of health, effects of biomedical intervention, and implications of genetic studies/treatments among this population, this work offers new knowledge relevant to cultural contexts of disease and advances our understanding of negotiation across cultural difference. Medical anthropology addresses the study of medical technologies and pluralistic medical systems that rely on both survival/nature and aesthetics/culture as materially embodied actors negotiate across difference. The anthropology of identity and action gives us tools to address actors' self-making and their participation in practice (Holland and Lave 2001) and aids the understanding of intimate senses of selves by framing theories of practice as rooted in socially informed bodies. Bourdieu suggests that the limits of objectivity might be superseded if we are willing to subordinate “scientific” operations to theories of practice, of practical knowledge, and of the limits inherent in objective knowledge (1977). Below, an overview of encountering the Amish in their everyday lives will be followed by a more detailed outline of the literatures and

theoretical approaches used in this dissertation to interpret and illustrate Amish society in the Lancaster settlement.

Amish and the Ethnographic Field

The Amish, writ large, are often treated as a homogeneous cultural group. In reality, they practice a spectrum of conservatism alongside their Anabaptist cousins. A social science inquiry in upstate New York would be drastically different than one in Lancaster County, PA, due to levels of conservatism, economic stability, relative wealth, and local history. This range from conservative to progressive manifests itself socially, politically, liturgically, and through forms of practice both mundane and ritualistic¹. The Amish are widespread with a population of over a quarter-million Amish living across 463 settlements in the United States as of 2012². The idea of Amish diversity is well known and explored by Amish studies scholars, but their multiplicity is often flattened in popular media portrayals such as reality television, serialized fiction, documentary specials, tourist materials, and the national press. It is true that Amish across the nation share a historical past, some sets of social practices, and a dedication to religiosity, however interpreted. But local groups exist in varied contexts characterized by variations in geography, economy, history, and relative degrees of separation from other insular contexts.

Social organization is also important for understanding the variety between and within Amish settlements. An acephalous society, the Amish church does not employ a centralized body

¹ See appendix 1: Spectrum of Current-day Anabaptists in North America.

² Population figures used throughout this study have been tabulated by scholars at the Young Center for Anabaptists and Pietist Studies and involve a combination of migration reports from district averages, the Amish newspaper *The Diary*, other correspondences in Amish print publications, Rabers Almanac, the official settlement directories, and informants inside Amish communities. For state-by-state data: (2012). "Amish Population by State." Young Center for Anabaptist and Pietist Studies, Elizabethtown College. www2.etown.edu/amishstudies/Population_by_State_2012.asp.

on a national or sect-wide level; there is no Amish Pope³ but simply a set of common histories, ideals, and practices. Meyers and Nolt (2005) authored a wonderfully apt metaphor of the Amish as a quilt patched together from different pieces but stitched by a unifying thread into an interconnected whole⁴. From the outside, Amish society appears to be a well-crafted quilt projecting an image of a plain, simple, ahistorical, and homogenous group. In reality, the Amish are a society of complementary yet distinct patches. All of these, I contend, are communities of practice engaged in building cultural worlds in a shared language of Amish society but simultaneously reflecting their own localities—particularly at the level of the church district.

Although non-centralized and without much formal hierarchy, Amish society does have three, overlapping forms of partition: the settlement, the district, and the affiliation. The settlement and the church district are both geographical divisions while the affiliation is an ideological one. The church district, or *Gmay*⁵, will be the most important concept of the three in the analysis to follow. These are individual churches, similar to the idea of a congregation in other Christian traditions. Nationwide, Amish church districts are home to between 20-40 households with an average of 137 individuals per district⁶. The districts in the Lancaster settlement are the most densely populated nationwide with around 165 people each.

³ Nor is there an “Amish Mafia,” despite the currently running (as of 2013), fictionalized television show depicting such an organization in a reality-television format.

⁴ Hurst and McConnell (2010) also reference this metaphor in their work on diversity and change among the Holmes County (Ohio) Amish.

⁵ *Gmay* is the Pennsylvania German form of the German terms *Gemeinschaft* or *Gemeinde*. These translate both as community or congregation. I use the spelling *Gmay* here, but it is also written as *Geme*.

⁶ For this nationwide data see: “Amish Population Trends 2012, One-Year Highlights.” Young Center for Anabaptist and Pietist Studies, Elizabethtown College. <www2.etown.edu/amishstudies/Population_Trends_2012.asp>

Leadership in the church rests at the district level. Each typically has a bishop, a deacon, and a couple of ministers⁷. Bishops may share two or three neighboring districts, but deacons and ministers are specific to the *Gmay*. These positions are held for life, they are appropriate only for men, they do not include any monetary compensation, and they do not involve any kind of vocational or theological training. These leadership positions are nominated from within the district by church members and selected by a process of drawing lots. This process and subsequent ordination are based in biblical scripture⁸. The ministers along with the bishop typically serve the theological needs of the church by preaching and officiating ceremonies like weddings, baptisms, or communion. The deacon along with the bishop typically serves the social needs of the church and may play a larger role in disagreements, reconciliation, accountability, and enacting the ban.

The boundaries of a district are many things—physical, social, flexible, resistant. The *Gmay* is the social body where primary collective identity is constantly formed, fortified, and enforced as it serves to minimize the autonomy of individuals in favor of group practice. To continue the metaphor above, the constant emergent strength of the individual district patches remains one reason this Amish quilt stitches together so nicely. Regional clustering of districts forms a settlement—another geographical distinction but not an operational one for any procedures of the church. Amish may identify as living on a particular settlement but their *Gmay* remains the driving referent for social and religious practice. Some settlements are regionally isolated and may contain only one or two districts. For example, there is only one district in the

⁷ It is worth noting that there can be gatherings of bishops but this is not to perform any kind of administrative tasks or make dogmatic decisions.

⁸ Members are nominated for these positions by anyone in the *Gmay* (women may nominate but not be nominated). The bishop places a piece of paper into a bible and sets a row of bibles out. All nominees take a book and the man with the lot in his bible is commissioned into ordination. “The lot is cast in the lap, but the decision is the Lord’s alone” (Proverbs 16:33 NSRV); “Then they prayed and said, ‘Lord, you know everyone’s heart. Show us which one of these two you have chosen to take the place in this ministry ...’” (Acts 1:25 NSRV).

state of North Carolina and it technically sits on its own settlement. Most settlements hold more than one district and the two largest, Holmes County area and Lancaster County area, hold 246 and 188 districts, respectively⁹. While leadership is tied to the *Gmay*, districts that identify along ideological lines form an affiliation.

Affiliations may form within and sometimes across settlements. Despite a wealth of differences, two major topics—shunning and standards for the youth—have widely been considered the major objects of contention that lead to significant schism and doctrinal differences among affiliations. This makes sense due to the ambiguity of these issues in biblical teachings, leaving both social shunning and control of the youth up to theological scrutiny and dispute (Hurst and McConnell 2010:56). Affiliated districts join as like-minded groups, they have leaders that cooperate well, they affirm similar community rules of order, and they have similar or identical approaches to acceptability of technologies both large and small. Affiliations can be recognized by a myriad of characteristics. For example: the Old Order around Lancaster use polyester cloth for their dressmaking while most Swartzentruber groups exclusively use cotton; many Old Order allow for a telephone placed outside the home (in a barn, shop, or outside shack) while New Order incorporate phones and computers into their businesses; Old and New Order Amish retain horse-and-buggy transportation while the Beachy Amish permit members to own cars. A settlement may contain districts belonging to only one affiliation or many. For example, the Holmes County¹⁰ area settlement mentioned above is the largest settlement by population size and includes eleven affiliations among its districts (Hurst and McConnell 2010:300). The Lancaster area, in contrast, is now primarily Old Order; the last of

⁹ (2012). “The Twelve Largest Amish Settlements.” Young Center for Anabaptist and Pietist Studies, Elizabethtown College. <www2.etown.edu/amishstudies/Largest_Settlements_2012.asp>

¹⁰ Although often referred to as the Holmes County settlement, it actually stretches across seven counties. Similarly, the Lancaster settlement is concentrated primarily in Lancaster County but includes districts in a number of surrounding counties.

the Lancaster New Order churches dispersed in 2012.

During my fieldwork in Lancaster County, I strove to meet and work with Amish families across districts to avoid essentializing the Amish as a monolithic group. I also made a few short-term trips to meet, interview, and interact with other regional Amish outside of Lancaster County including families in Somerset and Chester counties in Pennsylvania and Salem county in New Jersey—some of these families were in districts included in the Lancaster area settlement and some belonged to other settlements.

Due to the high population density in the area, Old Order Amish districts are not uniform hamlets. While a district is a geographically contiguous unit, an Old Order family may live adjacent to a number of non-Amish households or Amish and Mennonites from other groups. Although more rare, I even encountered families with more than one affiliation living on the same farm—the oldest generation remained Old Order while the next generation, often running the family business, worshiped in a more liberal, Amish Mennonite affiliation. Although the Lancaster Amish are not as diverse at the affiliation level as some of the other settlements, there are notable differences in wealth and relative conservatism among the Old Order districts in the area. Some of this has to do with proximity to the thriving economy in tourism.

Bringing out all of these variables is important for defining what I mean by *the Amish* as it gets used in this text. The vast majority of my consultants in this project were Old Order. In keeping with the population, the term “Amish” is used here to refer to districts from the Old Order in the most concentrated areas of the settlement—the central-east and southern areas of Lancaster county. Despite my exploration across the Lancaster settlement and into neighboring areas, this ethnographic data should not be stretched to become generalizable knowledge or representative of the Amish on a national or even regional scale—although I will occasionally

comment on the region as a whole. This project does trace some commonalities that exist inside this religious sect within a single settlement. But, as with most ethnographic work, it also exists in a singular time and space. We may learn about the dynamic cultural lives of the Amish in other areas via the experiences described here, but I make no claim to represent the lives of a generalized Amish populace or the experience of every Amish person in the Lancaster area or North America.

Project Structure and Case Studies

This project is particularly suitable for application of case study methods in contradistinction to practices of “apt illustration” and of extrapolating characteristics typical of an entire population. The focus here rests on lived practice and the concrete reality of the connections between and among various social characteristics (Evens and Handelman 2006) and practice. In chapter three, I outline the plurality of Amish health practices as a whole. Subsequently, chapter four opens up an in-depth discussion of culture and health by investigating one area of the plural system. It introduces the case-study structure which operates at two levels: focusing first on Amish use of genetic medicine via their relationship with the Clinic For Special Children in Strasburg, Pennsylvania, and then narrowing further by investigating the history and current dynamics around a specific genetic disorder, glutaric aciduria type 1 (GA1). Both of these case studies deserve brief introductions before moving on to other ethnographic considerations.

The Clinic for Special Children (CSC) sits at the end of a long lane, at the edge of a cornfield in rural Lancaster County, in an unassuming grey building with shape and detail reminiscent of a well cared-for barn. Just past the hitching posts in the parking lot, through a

waiting room often filled with women in apron dresses and white prayer caps, and around a crowd of similarly dressed children playing on the floor with wooden toys, the clinic's beautiful timber-frame construction houses modern clinical facilities and state-of-the-art research equipment. Like the population it serves, the clinic stands as a dynamic blend of tradition and innovation. The facility's staff specializes in over 100 genetic disorders. Its practice is recognized internationally as a leading treatment center for a number of diseases. The patient population is overwhelmingly drawn from the Plain communities, local Amish and Mennonites, who populate the Lancaster area. As clinicians and researchers, their goals include: identifying genetic causes of disabilities, improving diagnoses, and implementing novel therapies to create a cohesive strategy for improving pediatric health outcomes while reducing medical costs (CSC 2007). Simultaneously, the clinic aims to achieve these goals with constant attention to the cultural interpretations of its patient population and has achieved notable success in this endeavor. After spending years working to treat these Plain communities, it was the Amish and Mennonites that helped to raise the building housing the clinic.

These physicians and researchers have taken on a mission to make advanced medical technologies accessible, affordable, and culturally acceptable to the Plain folk in central Pennsylvania. They develop interventions addressing two major factors: methods for early diagnosis at birth and systematic approaches to managing diagnoses in both symptomatic and asymptomatic patients. Screening and treatments performed at CSC are regarded as pioneering and considered harbingers of a medical future based in new genetic understandings. The *New York Times* has called the clinic "a model and a test of medicine as it eventually will be" (Belkin 2005).

Glutaric aciduria type 1 is an autosomal recessive, metabolic disorder that occurs at

notably high rates among the Lancaster Amish. There are well over 200 known disease-causing mutations for GA1 in the general population with an incidence of over 1/100,000 (Kölker, et al. 2011). Worldwide, there are a number of genetic isolates that have been determined to have a much higher carrier frequency—including the Lancaster Amish. Among the Old Order Amish GA1 patients living in the Lancaster settlement, virtually all of them are homozygous for a single allelic change. Once known in this area as “Amish Cerebral Palsy,” or historically mis-diagnosed as acute viral encephalitis, injury from GA1 causes striatal necrosis of the basal ganglia. This injury most typically results in sudden, irreversible loss of motor abilities coupled with severe, crippling dystonia.

The incidence of GA1 in the Lancaster community is just above 1/300 births. GA1 provides an excellent case study for this dissertation for a number of reasons. This is one of the main disease states that brought Dr. Holmes Morton, the founder of the Clinic for Special Children, into Lancaster County. Wheelchair-bound Amish kids who could not speak or control their bodies had been showing up in times of dire sickness at Children’s Hospital of Philadelphia and John’s Hopkins for decades; many physicians and researchers pinned their issues to a problem from or at birth—thus the term temptation to chalk it up to a cerebral palsy. Dr. Holmes Morton was the first to change “Amish cerebral palsy,” into a more specific diagnosis and there by redefine its management. Subsequently, CSC was set up clinic in part to discover how to keep GA1 children healthy. A case study of this disorder, therefore, offers a view over time as the community’s relationship with genetic medicine has changed. It also offers a view over time as one clinic has shaped the way it practices medicine in order to accommodate its patient population.

Research Ethics, Naming, and the Interlocutor

As social actors with our own frames and dispositions, anthropologists can never be wholly separated from the conflict of interest inherent in studying other people. We now use the term “reflexive” with the weight of multiple senses; not only reflexive as to be aware of and take account of the self as both an affected and operative agent, but also as actions executed as reflex and lacking conscious thought (Davies 1999). While individual interaction between the limitations of the scholar and the understanding of the studied is worthwhile, it neglects this preconscious habitus. In that neglect we limit our roles as ethnographers, some still tempted by the farce of true objectivity, and some soothed into believing that collaboration can completely rectify the split between the other and ourselves. While collaborative design has recognized some of our own constructed fictions through a concern for ethnocentrism, ethnographic relationships must continue to emphasize our own and our consultants’ flexible identities with focus on the role of durable dispositions.

We narrativize, shape, and fictionalize our own lives; we struggle to control our synchronic experiences, and we are mediated by our diachronic experiences durably installed in the discipline of anthropology and the practice of ethnography. This reflexivity is implicit in a case study approach of situational analysis; the ethnographer, along with the collaborators, participates in social situations that balance responsibility and constraint (Evens 2006:58). Good qualitative research witnesses the ethnographer stepping away from strict diagnostic conventions and allowing the blurred lines between objective and subjective reports of culture to remain in all of their messy reality. Then, we are not only able to encounter our intrinsic subjectivities, but we

can reveal the cultural resources that allow our consultants to react to their circumstances in practice.

In that spirit and with the hope of being “good qualitative research,” this project involves analysis of social interaction over time with a constant attempt to recognize any assumptions deep-rooted in the analysis on the part of the anthropologist and on the part of the consultants. The social interactions discussed in this dissertation are nested from the center of Amish communities of practice on out: interactions between members of Amish communities, between the Amish and healthcare providers, between Amish cultural worlds and cultures of biomedicine. The relationships between Amish and the various domains they access (technology, medicine, socio-political power of the State) involve conflict resolved through constantly striving to enact and maintain a collective identity, regulated by their own body politic, and made manifest by embodiment and material.

It was rare to meet someone new in the course of my fieldwork and not have that person comment on the “Amishness” of my name. That goes for members of the Amish community, people at the Clinic for Special Children, health practitioners that work with the Amish, Amish enthusiasts, Mennonite history buffs (there are more of these in Lancaster than you would think), and even other academics working in Amish Studies. Virtually every Amish person I met and most people from these categories all commented in some way on “Martha King.” I was assumed to be Amish when others heard about me word-of-mouth, I was constantly directed to a common Amish genealogy, typically referred to as *The Fisher Book*, to turn the pages and show where I fit in. I had not known many Marthas in my lifetime before heading up to Pennsylvania but when I left, I’d met four Martha Kings, and one of them shared my middle name as well. The surname King has the second highest frequency among surnames in the Lancaster Amish settlement—

roughly 1-2 of every 10 individuals has the last name. And Martha? Well, that's just good biblical tradition.

Another concern, of course, in addressing reflexivity and assumptions in both data and analysis is recognizing the positionality of the ethnographer in the field. Working in two distinct cultural worlds and exploring the discourse between them meant becoming aware of my own position in each. In either setting (and in the places where they overlapped), there were *different* elements of who I was and what I was representing that were curious and familiar. Spending time in Amish homes and working with Amish participants was made easier because of my status as a mother, a wife, and a Mennonite. At the same time, I was often questioned about working outside of the home with such a small child, leaving my husband back in North Carolina when I went to the field, how conservative my home church was, and what kind of work this was to be just talking to people all the time¹¹. Conversely, spending time at CSC and with many of the other healthcare practitioners of one kind or another was made easier because of my status as an academic and a student. At CSC in particular, they are used to a constant trickle of scientific students from undergraduates to medical fellows coming through or expressing interest in learning more about what goes on there. In that way, I made sense. At the same time, my disciplinary separation from the physicians and staff at CSC was constantly palpable. They've had little long-term interest from social scientists and it was clear that my work, while deemed interesting, did not hold the same kind of consequence or meaning as many of the other students coming through that space.

CSC, however, was one of a couple major gatekeepers for my work, both in their

¹¹ I count myself in what has got to be a long line of anthropologists who have worked with communities that have virtually no idea what anthropology is, what it's good for, or how I could possibly be "hanging out," all day talking to people without getting paid or doing any real work.

willingness to help me access their patient population and in the cachet it provided me in the greater community to be working with such a well-respected group of English. Otherwise, it is true that Amish communities are notoriously difficult to study; they don't particularly care for the outside gaze and they've been treated poorly in the past through various forms of media. Imagine my surprise to realize that the first thing to make me familiar, the first thing to get my foot in the door with some consultants was my name. And it was even better that I could legitimize that name beyond mere coincidence. My surname¹² does indeed come straight out of Lancaster County Amish.

We concern ourselves as researchers with problems and histories of representing the worlds of others. And formal bureaucracies concern themselves with these problems in our research as well, to some extent. Institutional review boards attempt to guarantee ethically proper treatment of participants and one of their measures requires the protection of privacy of "human subjects."¹³ Constructs of requisite anonymity for project participants have been upset in some areas of Anthropology through the incorporation of openly collaborative methods that effort to equalize some of the issues of authority in ethnographic relationships. These methods include full involvement of those participants in the creation of an ethnographic product¹⁴ and open

¹² King is my married name, but this designation did not seem to matter in such a heavily patriarchal group. My imagined inclusion was usually intensified by the fact that I am a mother—not just a King, but responsible for carrying on (Amish) King blood. A consultant even put this to me blatantly when I pointed out that my background was not from Lancaster. "But you're a King in any way that *matters*. And look her—[your daughter], she'd make a good Amish girl just like what's in her blood!"

¹³ I put the term human subjects in scare quotes because despite its use by IRBs and in biomedical research, many in the social and behavioral sciences have rejected this term. No one in this project will be referred to as a subject to refrain from placing them in a hierarchy of power between researcher and the researched. Instead, people are referred to here as consultants, participants, or interlocutors in order to recognize their agency. Arguably unattainable, one goal here is to equalize the researcher to a kind of partner with her participants or appropriately reduce the researcher to a student available to learn about the everyday lives of those she studies. Note that this project was carried out under approval of the IRB at the University of North Carolina at Chapel Hill.

¹⁴ See Eric Luke Lassiter's work *The Chicago Guide to Collaborative Ethnography* (2005) for a full discussion of this form of collaboration. As his work discusses, the guidelines set there can be large goals to meet and often tumultuous for both ethnographer and consultant. For a discussion of the potential bind created by over exposure in collaborative work see (King 2010).

identification of participants as co-authors.

In contrast, I found that my Amish consultants were most comfortable with or even requested a more traditional, IRB-style approach to enrollment. Anonymity and dissociation from identifiable data were particularly Amish-friendly approaches to recruitment. Going so far as to accept a researcher into their relatively closed communities was sometimes enough of a social stretch; openly identifying individuals, districts, or families in a research product would not be an acceptable option. However, in other areas of the research, some elements of open collaboration remained situationally appropriate and methodologically sound. Open collaboration proved to be a good method for combatting the fact that I could not provide a shield of full anonymity for the physicians and staff at CSC—they are a discrete group of interlocutors and it would be virtually impossible to incorporate their side of the story without discussing the specifics of the clinic’s history, location, and current practices. This was disclosed at the time of consent, but I have still taken steps to make some of their comments anonymous when appropriate. Generally, the physicians, the head of the lab, the nurses, and the executive director at CSC are referred to using real identifiers. There are times where “a doctor” or “the physicians” stands in as a general referent. Other support staff and visitors—office staff, consulting physicians, visiting students—are kept anonymous.

In light of collaboration and privacy, this analysis utilizes two special sets of representational considerations. Amish consultants, clinic patients, and health practitioners outside of those at CSC agreed to participate in this project through a process of informed consent with an assurance of anonymity. In the narratives and analyses to follow, those individuals and families have been protected in two ways. First, all names have been changed

with one exception¹⁵. Due to the small number of Amish surnames in the Lancaster area, I have chosen surnames that are less common in Pennsylvania. Surnames used here have Amish or Anabaptist heritage but occur at 1% or less in the Lancaster settlement. The name Troyer, for example, is a common Amish name in the Ohio districts and some other parts of Pennsylvania but only represents 0.08% of the Lancaster area Amish. In contrast, Stoltzfus and King are the most common names in the Lancaster area, at 27% and 12% of the population respectively¹⁶, and are therefore not used. Other common names from Lancaster include Fisher, Lapp, Beiler, and Esh. Many of the names used as pseudonyms in this dissertation come from the common surnames in Ohio and the Midwest—Troyer, Hochstetler, Schrock, and Hershberger—or from the common surnames among Swiss-Amish descendants in the Indiana area—Graber, Wittmer, Schwartz, and Lehman.

The other method I have incorporated is to intentionally conflate multiple similar experiences with representative personas. This method was particularly helpful for sections discussing issues at the clinic and around GA1. For example, I interviewed close to a dozen families with one or more children who have been diagnosed with GA1. Among those, three families had older children and had been affiliated with CSC from its early years. These parents and children, some of them now adults, have been through similar experiences on similar timelines; the Miller and Troyer families represent them here. The Wittmer family represents Amish families with GA1 children who were still young and undergoing active interventions at CSC or are part of the current CSC research cohort for GA1 infants.

¹⁵ The Miller family, one of the first families that worked with Dr. Morton when he arrived in Lancaster County, appears here with no name change. The Millers already appear in publically available published materials with their real names. They have also, at times, acted as unofficial spokespeople of CSC by traveling with the physicians for talks or visits to more rural Amish communities.

¹⁶ From unpublished census data from 2011, Young Center for Anabaptist and Pietist Studies. Similar percentages are represented in (Strauss and Puffenberger 2009).

Driving Questions

As mentioned above, this project moves from delineating the breadth of health practices among the Lancaster Amish to the details of their interactions with translational genetics. At the widest level, this research asks *how are Amish understandings of health and the body shaped by culture in ongoing practice?* To answer this question, I will sketch out a plural medical system used by the Amish and discuss how the cultural practices inherent in collective cultural identity formation inform this plural system. This requires identifying the potential areas of cultural practice that impact how Amish experience their bodies in the world. Using health—and particularly, healthcare—as a lens requires identifying how diseases are understood by members of the Amish settlement as well as ways this may differ from the local biomedical community. For example, what social responsibilities, etiologies, preferences for clinical care, or issues of cost are expressed in the narratives told by Amish? With the absence of science education in Amish schools, what sources inform their conceptions of the body, health, and medicine? Although contemporary studies of genetics often focus on kinship relationships, how, if at all, are these categories used by Amish families to understand treatment procedures or disorders?

Biomedical systems are elaborated upon as one strand of this plural system. This research asks *how do local Amish cultural identities and standards about technology undergo modification in light of Amish desires to access the benefits of modern genetic medicine?* To answer this question, I will bring in the case of CSC and discuss how Amish negotiate, accept, and reject highly technological, individualized medical models and technologies in the setting of

translational genomics¹⁷. The case will help establish how community members reconcile clinical knowledge and practice with their cultural identities including how families ascertain the culturally acceptable levels of engagement with biomedicine. For example, what roles do families, districts, church teachings, and perceived authority of medical personnel play in potential areas of contention between Amish worlds and biomedical approaches? How do firm social standards for marriage and kinship practices impact patient understanding of disease patterns with strong genetic etiologies? Are there situations when the spirit of a group identity is bent or broken by articulations of medical autonomy? Are there indications that these aspects of cultural identity are being reformulated as a result of the encounter between clinic personnel and Amish families?

Lastly, narrowing the focus even more, this research asks *how practitioners at CSC accommodate aspects of Amish cultural worlds in the organization of their clinic and what impact that has on both communities of practice?* To answer this question, I will employ the case studies of CSC and GA1 to discuss the clinical encounter alongside the impact of group-centered identity on healthcare outcomes. This project allows me to use healthcare as a lens for understanding how the collective sense of what it means to be Amish in the Lancaster settlement is developing in response to the availability of the Clinic for Special Children. This will create a space for determining topics of cooperation or contention between the Lancaster community and the Clinic for Special Children, the impact of these on the clinical encounter, and possible implications for the field of genomics. For example, what changes do physicians report having made in their clinical practices to accommodate Amish patients? Does the patient's spiritually-

¹⁷ Translational genomics involves attempts at combining bench science with clinical care in an effort to create spaces where basic research may directly impact patients. *Nature Reviews: Genetics* keeps an index of their published articles that fall into this category: (<http://www.nature.com/nrg/series/translational/index.html>)

based understanding of the body affect the relinquishing of that body to traditional biomedical procedures such as blood draws, vaccinations, physical exams, and pharmacological or environmental treatment methods?

Methods and Approach

The field research phase of this project included three primary components: (1) participant observation, (2) mixed qualitative / quantitative survey data, and (3) semi-structured interviews. As a participant observer, I lived and worked in Amish households, shadowed clinic visits at CSC, and participated in various Plain community events from religious services and community gatherings to annual fundraising auctions held by Plain communities to support CSC. In collaboration with Donald Kraybill at the Young Center for Anabaptist and Pietist studies, I also developed and administered a survey to Amish community members to gauge general Amish health practices¹⁸. Lastly, I interviewed consultants across the Amish settlement, clinicians and staff at CSC, and other types of health practitioners working with the Amish.

In addition to outlining a model of Amish health as it is understood from inside the community, my data analysis attempts to parse out points at which Amish religious practice impacts use of biomedical healthcare, specifically in the realm of translational genetics. This data was analyzed using a hybrid of evaluation types. Coding and compilation of the data took elements from narrative analysis and content analysis; results from all three of the research components listed above were scrutinized following the research themes summarized above using analytic induction. Interviews, field notes, and observation notes were coded to locate

¹⁸ This survey was implemented over the course of a year in a limited number of districts. Despite the useful data we were able to draw from the results, it was not a large enough or diverse enough sample to be considered representative of the settlement as a whole. It does offer us a good idea of possible trends in the area as well as providing preliminary data for a future, in-depth quantitative study. This data is discussed in Chapter 3.

explanatory, networked accounts of Amish health, interactions at CSC, and GA1. I formulated findings addressing the driving questions and research themes, subsequently searched for negative cases, and finally revised my account until all cases could be explained.

Once these accounts were developed, I approached the structure of my data in the tradition of the Case Study method explored by the Manchester School. Amish healthcare systems as a generalized picture, the dynamic situations at the clinic, and the specificities of GA1 families all constitute layered case studies. And thinking of them as such layered case studies is indeed heuristically valuable; the events portrayed therein reflect features that may be construed as a manifestation of a theoretical principle (Mitchell 2006:28). These types of extended case studies uncover a higher order of complexity than is the case with apt illustration or slightly more compound analyses of social situations (Gluckman 1961:5-7). This use of cases here echoes the kind of situational analysis outlined by T.M.S. Evens—approaching a case this way may be understood as a “precocious exercise in practice theory” (2006:57). The goal here is to reject assumptions that action is *preceded* by culture, that theories can be easily mapped onto a group of people, or that theory is a function of cultural structures. Instead, we can look for theory emerging as a “coefficient” in cultural practice and hope this might reveal to use something about the “character of social existence”. As with practice theory, this places primacy on action, reaction, and interaction of the people and objects in a cultural world and the case study draws borders around this placement in a specific place over a determined amount of time. All of these results come together to build new understandings of lived-faith among the Lancaster Amish and how their expressions of community identity interact with realms of genetic medicine.

At the widest level, this project uncovers models about Amish health and illness by recognizing discussion around personal illness as a mechanism for transmitting social knowledge

(Linde 2001), as actors respond to the situations through which they navigate their bodies in the world and demonstrate tacit understandings of their perspective. Cultural meanings color myriad aspects of the everyday, including experiences with one's own body, illnesses, dis-ease, and health. In order to ascertain how Amish among the various Lancaster districts respond to and participate in negotiations with their plural model of health, this project uncovers some of the culturally shaped knowledge concerning the body and illness.

At the clinical level, I looked for the factors Amish actors take into account when they participate in biomedical decision-making and the cultural resources they rely upon in interactions with clinical care at CSC. Likewise, I looked for the factors biomedical actors take into account when they participate in Amish society and the (medical) cultural resources they manipulate during interactions with their patient population. As outlined below (and further in Chapter 2), group identity in the cultural worlds of Lancaster Amish church districts assumes a stringent relinquishment of self-will for the benefit of community well-being as the community actively eschews individualism and views the body as a divinely-dictated, spiritual home (Kraybill 1989). In sharp contrast, biomedical systems the Amish commonly traverse are steeped in deference to the body as the possession of the individual and the terrain for autonomous, independent selfhood. Understanding the biomedical conceptualization of autonomous personhood being a natural link between an objective body and subjective spirit (Foucault 1970) while simultaneously recognizing Amish approaches as something wholly different from that approach, the CSC model that has been co-produced by the biomedical personnel and Amish patient-families may be established as a complicated, if successful, frame for collaboration between medical models and patient populations who approach the exam table from drastically different ontological positions. This is illustrated at a deeper level when I further my focus to a

specific disease. Here, I use the illness narratives told by Amish families and those told by practitioners at CSC as the key methodological component for the GA1 case study. Illness narratives contain components that “are drawn from cultural and personal models for arranging experiences in meaningful ways” and provide access for understanding the personal and social contexts involved in illness (Kleinman 1989).

Theoretical Frameworks: Cultural Worlds of the Amish

Here, I take up the term “community of practice” as defined by Lave and Wenger: sets of relations among people, non-human actors, and activities over time and in relationship with other communities—these are “an intrinsic condition for the existence of knowledge” (1991:98-100). This holds true in the communities of practice enacting cultural worlds of the Lancaster Amish. The Lancaster Amish inhabit a world where Christian faith is not separable from daily life. In turn, their standards for that everyday practice inform and are informed by a mutual identity at the group level at the *expense* of autonomy and individualism. Vygotsky (1978) and other theorists of the social formation of mind and self argue that individuals cannot be understood separate from their surrounding societies and this holds doubly true among the Amish. Formed through participation in everyday Amish life, Amish individuals reproduce a community space that intentionally subsumes the individual, placing primacy on a well-elaborated, collective group identity.

Drawing on George Mead, Bakhtin, Vygotsky, Bourdieu, Lave, and Holland, social practice theory recognizes group identity as being constantly “fashioned and refashioned with the cultural resources at hand” (Holland et al. 2008:121). Over time and space, a collective identity emerges through and as a product of “social conduct”. These identities are not products of

isolated, deliberate processes of cultural production but are dialogically shaped within communities of a dynamically changing cultural world (Holland et al. 1998 ch. 3; Holland and Lave 2001:9- 12; Satterfield 2002:6). These cultural worlds can be thought of as realms where social participation develops as individuals come together in the community of practice around shared concerns, confront conflicts, and encounter difference. As collections of Amish individuals participate in these religious, familial, and community-based groups, they also form senses of self in these realms. On an intimate level, identities develop relative to the participation in that community of practice and its performance of the cultural world and relative to the actor's agency and embodiment of the activities, acts, and outcomes bounded by that world. In other words, group identity can be understood as the collective sense that is produced by and significant to a set of actors through their joint activities and commitments (Holland et al. 1998, Holland et al. 2008, Wolford 2010). The Amish both author and are authored by these collectively produced horizons of meaning against which action events are interpreted.

Discussion around formations of collective identity as a driving factor for group engagement is especially emphasized in the social movements literature¹⁹. In their work on social movements, Holland, Fox, and Daro highlight three dialogical processes occurring in the (re)forming of collective identity: “the development of cultural worlds in relation to which movement actors act and imbue their movement identities with meaning; ongoing importance of dialogic exchanges between the movement and other social actors; and the effects of cultural artifacts that mediate effects of the movement and the formation of identity” (2008:119). While Amish society during its inception and migration out of Europe could be understood as a social movement concerned with being a “dynamic force for change” (ibid:97), its eventual stability in

¹⁹ See Polletta and Jasper (2001) for a review concentrating on “sociological treatments” of the concept that focuses on the “movement dynamics in which identity may operate.” (285-286).

North America has rendered the Amish a sort of post-movement. Beginning initially as a spiritually-based social movement, their terrain of struggle can be conceived as the sect's centuries-long, self-conscious efforts at maintaining cultural separatism (Hostetler 1980) and constant related endeavors to negotiate the modernizing world. Yet, having reached, sometimes painfully, many of their original goals—religious freedom from the state, social separation, liberty to abstain from sanctioned violence, dogmatic autonomy—Amish settlements have become a thriving, stable society with a constantly expanding population. In fact, their group identity solidifies in a form that explicitly separates them from the social movement paradigm in two crucial ways. As opposed to the constant struggle within social movements to have collective identity deeply inform intimate (personal) identity (eg. Polletta and Jasper 2001), Amish communities have become organized such that what it means to *be* Amish actively builds personal identity by way of longstanding group practices. Further, in movements, the collective often focuses on “rewriting the cultural landscape” for society as a whole through contentious dialogues (Satterfield 2002:9). The Amish, by contrast, work from a desire to remain at bay from outside social discourse. In other words, despite the attention paid to them from the non-Amish gazes, they are simply not interested in transforming outsiders or even *being relevant* to or in larger spheres of influence.

While they do come up against internal²⁰ and external conflict, the sedimentation of their cultural identity within the communities of practice constituted by church districts provides a firm embankment from which to engage antagonizing forces. But despite these separations from the social movements paradigm, the three dialogical processes outlined above still hold true.

²⁰ See Hurst and McConnell (2010) for discussion of conflict between Amish affiliations in the Holmes County (Ohio) Amish. While the Lancaster Amish certainly engage in inter-Amish conflict, the Lancaster area is comprised of almost entirely Old Order Amish. Unlike the Holmes County area, with almost a dozen varied affiliations, Lancaster Amish are relatively more homogenized.

First, the Amish continue to shape and develop cultural worlds relative to the religious and social meanings maintained by actors within their communities. Second, they constantly (particularly in the Lancaster area) engage in social, economic, political, and spatial exchange with other social actors outside of Amish communities. Lastly, cultural artifacts and materiality both mediate effects of the group on outside actors and play a dominant role in the cohesion of Amish group identity. These themes—developing and performing cultural worlds within a community of practice, exchange with outside actors, and the role of cultural artifacts will arise again and again in the work to follow.

Antithetical to western ontologies, expressions of individualism are deterred in the Amish worldview; this holds true across varied church districts, affiliations, and settlements. Children learn to reproduce a lack of consideration for themselves as individuals and this perspective becomes sedimented in their everyday interactions. Later, an explicit, dramatic dismissal of individual concern is made possible first by a temporary exploration and expression of the self via *rumspringa*—the time period a teenager (typically some duration of time between 15 to 19 years old) spends outside of the community and its practices— and the subsequent forfeit of self-interest during voluntary unification with the church community through baptism. The entrance into the church, in other words, can be seen as a rite requiring true sacrifice; one must kill or surrender the autonomous self that was exercised in *rumspringa* in order to remain in/be welcomed by the community and thereby receive cultural and spiritual salvation.²¹ This group identity centered on self-sacrifice, particularly at the level of the *Gmay*, or church district, is an aggregate assemblage from cultural resources that are themselves a form of practice (Friedman 1992, Holland, et al. 1998).

Taking up the lamination metaphor put forward by Holland and Leander (2004), lastingly layering or winding raw materials together provides the finished product with a unique, durable,

²¹ See Chapter 6 for further discussion of baptism as self-sacrifice

and functional shape. They offer the drum as one example; the body of a drum is often constructed by fusing thin layers of wood. Likewise, bringing together different materials—like a paper document or label with a plastic cover—creates an end product that has recognizable constituents and behaves resiliently. It is a fitting metaphor for Amish homogeneity, particularly the way that members of Amish communities of practice come to be treated by themselves and others as “Amish”. Amish settlements bring together the raw materials—Amish individuals, spaces, and cultural artifacts—and they become laminated together *in practice*. Like the combinations of heat, pressure, and glue on layers of wood or plastic, community praxis drives the action of laminating together Amish individuals into a cohesive, durable collective. This collective actor is clearly expressed in Latourian ideas of the “social” dynamic moments of association that gather actors, spaces, and artifacts into new forms (2005:64-69). While it is true that lamination lets us see and even feel the product’s constituent parts, the process is transforming, rigid, and even disfiguring. Un-laminating an identification card or a sheet of plywood is not an easy task and often the smaller parts cannot be removed without significant damage. As it is with the Amish; instead of focusing here on the production of persons in turn or their positionality, the Amish demand the assembly of a solid, laminated cultural whole that irreparably binds its members to the identity of the group. While individual expression and attitudes are certainly maintained, the subordination of those individuals to their communities is “the fundamental key that unlocks many of the riddles and puzzles of Amish life” (Kraybill 1994:30).

Stepping back, it is useful to restate this process of the lamination of group identity as the collective sense that is produced and internalized by a set of actors through their joint activities and commitments (Holland and Lave 2001). Instead of coming together with the purpose of a

united force for specific action, in Amish society those group activities and commitments loop back and consume the set of actors enacting them, thus creating a solidified community of practice that makes itself conditional on the cohesion of the whole. The use individuals make of “common classificatory systems,” quite literally comes to define individuals’ ideas of themselves as a “whole social being” (Bourdieu 1984:478-479). Investigating Amish cultural worlds requires a delicate balance between addressing individual actors’ self-making and individual actors’ participation in community practice that moves to diminish their own individual agency. They create culture amid this series of tensions: between the self and the overriding group identity, between the group’s cultural world and larger spheres of influence around them, and among the cultural artifacts aiding that durability. This system puts the “social” into “social practice theory,” thereby signaling an effort to begin everyday social lives where structures and subjectivities “co-occur and are patently historically specific and spatially located” (Holland and Leander 2004:130).

Theoretical Frameworks: Medical Pluralism, Practice, and Technology

Looking at Amish health and healthcare provided an excellent venue for recognizing both natural and cultural elements in local health systems. This, in turn, provides opportunities to blur the boundaries of subjective/objective dualisms. Maintaining such a vision for medical anthropology involves struggling against a continued modernist separation of mental, subjective experience and bodily, objective experience in order to recognize the fluidity of a cultural-biological divide (Latour 1999, Lindee 2003, Scheper-Hughes and Lock 1987, Strathern 1992, Taussig et al. 2003). A useful tool from anthropology for discussing the body in the world is to recognize its personal, functional, symbolic, and regulatory existence. Scheper-Hughes and Lock

provide a helpful frame for incorporating all of these overlapping elements and continue problematizing dualisms; their “three bodies” offer one way of talking about the interplay and influences among the individual body, the social body, and the body politic (1987).

Further, the Amish offer us an opportunity to continue removing classifications of natural, tightly bounded cultural groups that anthropology inherited from the colonial control over the marginalized “other”. Instead, illness and the health encounter in Amish communities have become illustrative of pluralistic systems that require attending to how actors participate in negotiations within realms of difference both internal and external to their group identity and always mediated by cultural artifacts—in this case, medical or otherwise body-related technologies.

Health and the body provide one arena where these three tensions are played out in the Lancaster Amish communities I worked with. The Amish build and participate in a pluralistic system of healthcare rooted in socially informed bodies. In other words, the co-occurring structures of Amish social lives and the subjectivities formed in those lives play heavily into how they negotiate illness, disease, healthcare, and social wellness. With this “body” they experience the tensions that arise between the self and their community, among their community and the outside, and around the artifacts that populate their cultural world. And those bodies, like any other, are dynamic players in the cultural world as individual experiences around health and illness become symbolized in the social body (Scheper-Hughes and Lock 1987). Those bodies are clothed in Amish identity just as they are clothed in Amish garb. Those bodies suffer illness, death, indecision, hard work, and serve as the filters for perception in the world. And most relevant here, in their doing-as-bodies-do, they require attention, care, and even intervention.

Since the 1970s, medical pluralism and the “plurality of care-seeking strategies” have

been perennial themes in medical anthropology (Castro and Farmer 2007), and Arthur Kleinman's label of medical and health practices as cultural systems (1978) opened up these pluralities as uniquely suitable for anthropological study. Often conceived as a cosmopolitan versus indigenous dynamic (Leslie 1980), medical pluralism has come to encompass additional constructions of plurality including the more recent focus on implementation of medical and health technologies in practice (Lock 2007). In the presence of choice between medical settings and technologies, members of a cultural group are faced with decisions, and sometimes dilemmas, as to what approach (or combination of approaches) may be most suitable, most socially acceptable, and most effective in addressing the body. Kleinman notes that these kinds of decisions are typically made in what he calls the "popular arena"—the family, social network, and community contexts of sickness and care (1978). For the Lancaster Amish, decisions are certainly made in all of these arenas but normative health practices and the suitability of health technologies are intensely impacted by treatment seekers' sense of themselves as part of an Amish collective. Paying attention to how actors talk about health decisions offers insight into the nature of cultural knowledge as it is employed by community members with respect to illness, how this knowledge is applied to interpreting and evaluating illnesses, and the processes whereby treatment decisions are made (Garro 1998, Crandon 1986).

Unlike the larger, national medical context in which biomedicine holds dominance over other medical practices (Baer 2004), the Amish pluralistic system reflects their hard-won, faith-driven, intentional removal from dominant, state-related hierarchies. Baer emphasizes that ethnic and class minorities use various forms of pluralism to challenge the dominance of biomedicine and elite hegemony. However, in the Amish case, the engagement of pluralism results less from a challenge to hegemonic forces and more due to Amish communities' intentional, explicit

separation from the structures that govern “empires of man”. Instead, their system incorporates a small array of health approaches specific to the context of affliction. These approaches tend not to dominate or subordinate others (i.e. a “traditional” or indigenous healing system subordinated by biomedicine or the reverse) because each is appropriate and relevant to its own class of bodily states. In Lancaster, these plural approaches run along in five strands—each used for the most part to attend to specified sets of concerns: chiropractic care, used as preventive medicine and for minor injuries; homeopathy and herbal medicine for preventive care, some cases of acute care, and in complement to other modalities; midwifery with both lay-midwives and biomedically-trained midwives for all gynecologic, obstetric, and neonatal concerns; local biomedical intervention for intense trauma, genetic disorders, and some long-term illnesses; and medical tourism (primarily to clinics in Mexico) for serious dentistry and attention to some long-term debilitating illnesses.

Each of these strands—chiropractic, herbal/homeopathic, midwifery, biomedicine, and medical tourism—will be briefly explored as parts of a whole pluralistic system in the work to follow²². For the purpose of this work, however, I will pick up the thread of biomedical services as a case study and focus on local availability and negotiation around translational genetic medicine. This case study will be introduced in detail below and developed throughout the body of this work. Despite a healthy Amish studies literature, there is only a small body of primary literature addressing cultural ideas about the body or healthcare in Amish settlements (Gallagher 1988, Wenger 1988, Waltman 1996, Campanella et al. 1993, Bassett et al. 1994, Graybill and Arthur 1999, Graham and Cates 2002, Huntington 2003), and few specifying any socio-cultural aspects of genetics among the Amish (McKusick 1978, Brensinger 1995, Francomano 1996,

²² See Chapter 3 for a full construction of the plural medical system used by the Lancaster Amish.

Morton et al. 2003). Because the Amish provide a consistent study group with a higher incidence of genetic disorders than the population at large (Francomano 1996, Strauss and Puffenberger 2009), geneticists have worked in varying capacities with the Amish population across North America for the last 50 years. Dr. Victor McKusick, one of the first and most well-known medical researchers among the Amish, outlined fifteen distinct characteristics of Amish social life, biological makeup, and cultural practice that make them uniquely “useful for genetic studies” (1964)²³.

Pluralistic medical practices and choices have advantages for cultural strategies (Kleinman 1978), and anthropology’s work with the health encounter offers important insights into what can happen in these settings. Decisions made in Lancaster Amish church districts regarding the use of genetic technologies are delineated by and heavily influenced by the cultural practices and group identity introduced above. The resulting situation offers a clear instance of new healthcare options being introduced into a community in need around Lancaster; sets of people have been suddenly brought into relationships with new knowledge and technologies. Frequently, these technologies and scientific efforts presume and/or create expectations of persons as self-conscious, autonomous subjects (Adams and Pigg 2005). Consistent with their training, biomedical practitioners often deal with individual patients as discrete units. This creates an immediate disconnect in the church districts around Lancaster, as well as in Amish settlements all over North America, as they foster cultural understandings that expunge individual expression and place a primacy on the group. The clinicians at CSC have attempted to make adjustments to this model in order to serve their patient population. This dynamic combined with the community-determined standards on use of technology and the fact that

²³ See Chapter 4 for a full discussion of Amish population genetics and McKusick’s outline for Amish utility to medical genetics.

Amish communities were not geographically remote from the “rise” of modern understandings of the body are all unique historical and cultural circumstances. At the center of these circumstances are the interactions between patient families and practitioners negotiating across cultural difference. The negotiations that occur between local illness careers (Csordas 1988, Fabrega and Manning 1972, Pescosolido 1992) and interactions with types of medical treatments are important factors in shifting socially constructed definitions of disease (Mishler 1981, Waxler 1981, Lindenbaum and Lock 1993, Mattingly and Garro 2000).

Theoretical Frameworks: Embodiment and the Body

In some ways, the concept of embodiment touches on many of the concepts above. This research looks for those meanings in order to advance understanding about the implications of bodily practice for group identity (Farquar and Lock 2007). As already reiterated, church districts explicitly place primacy on the group at the expense of the individual (Kraybill 1989), collapsing autonomous agency into group practice and further strengthening the cultural world performed in this community of practice. This brings medical matters and the body into interaction with collective cultural identity and cultural practice in order to explore understandings of the cultural delimiting of “the body” and how it interacts with illness. As emphasized in medical anthropology, bodies exist simultaneously as objects and subjects among healthcare professionals and the patients they treat, and they exist as the terrain where social truths and contradictions get played out (Scheper-Hughes and Lock 1987).

Phenomenology discusses intimate, individual identities as formed through the body as the locus of experience and subjected via that embodiment to relationships with other selves (Levinas 1998, Merleau-Ponty 2002). Mauss’s habitus affixed cultural practice to the body

(1935), and Bourdieu's expansion of the term added bodily dispositions reacting to both perception and action, thus incorporating the objective social realms into the subjective experience of the self (2006). As Bourdieu concentrates on individual consciousness as "socialized subjectivity" resulting from internalizing social forces (Bourdieu and Wacquant 1992), this work moves along the particularity of bodily practice and the process of subject formation to refocusing back out on the social body—the body as collectively constructed in practice. A sense of individual bodily experience is thus shaped by the collective identity of the group and vice versa (Scheper-Hughes and Lock 1987). I will look for this relationship while researching subjects' self-making and their participation in practice (Holland and Lave 2001). Healthcare and the body may be used as a lens to see how social participation in a Lancaster church district shapes self-authoring.

Answering that question addresses forms of embodiment in fields of practice by reading the dynamic between bodily practice and group identity (Farquar and Lock 2007) in an active religious community. Csordas' call for embodiment as a paradigm in anthropology is particularly useful here; his approach grounds practice in the socially informed body and provides a model by which Merleau-Ponty's preobjective and Bourdieu's habitus "guide analysis in the empirical domain of religious experience and practice." The analysis of perception and practice grounded in the body not only collapses subject/object dualities, it can open up investigations into how selves are constituted throughout the flux of cultural life (Csordas 1990). For example, Csordas illustrates how categories of the sacred in religious healing are made operational by their otherness and are therefore, an expressly ethnographic problem. Embodiment offers a methodological ground for empirical, ethnographic identification of such otherness (*ibid*). This will prove important in discerning how districts in the Lancaster settlement, bound by cultural

and sacred commitment to the group at the expense of individualism, reject or enact social and biological autonomy in the face of biomedical technology and the otherness it represents.

Chapter 2: Historical and Cultural Contexts of the Lancaster Amish

Anabaptists

The Anabaptist movement got its name from the practice of “re-baptizing” adults with water. This religious group came out of the Radical Reformation and refused to baptize infants on the grounds that young children do not have the experience to grasp a call to follow a spiritual life centered on the teachings of Christ. From the Greek *ἀναβαπτισμός*—over again + *βαπτισμός*—baptism, the Anabaptist movement has a complex historiography²⁴ and the term itself originated as a marker of heresy. Within the group, most called themselves Brethren instead of Anabaptist. The first recorded adult baptism was held in Zurich on January 21, 1525 in defiance of the city council’s directive (Dyck 1993). In 1527, they became informally bound together by a set of articles ratified in a secret conference of church leaders. These directives became known as the Schleitheim Confession²⁵.

Despite being hunted and persecuted by the theocratic state, in the 1540s these followers congealed under a temperate leader, Menno Simons, and soon became known as Mennonites. In addition to adult (re)baptism and refusal to baptize infants, early Mennonites were set apart from both Catholic and Reform/Lutheran churches by their insistence that a church body must come

²⁴ The genesis of the Anabaptist movement does not spring from straightforward set of events and scholars debate the details of its early development. Snyder’s attempt (2006) to bring together various approaches to early Swiss Anabaptist history accounts for both religious and socio-political motivations. Its development of the topic is well treated; likewise, the published responses (Baylor, et al. 2006) to his set of articles are instructive as to the nature of this historiographical shifting.

²⁵ A good bibliography of writings about the Schleitheim Confession can be found here: Wenger, John C. and C. Arnold Snyder. (1990). Schleitheim Confession. Global Anabaptist Mennonite Encyclopedia Online. <http://www.gameo.org/encyclopedia/contents/S345ME.html>

together voluntarily and separate from the state. Communities of believers would form the Mennonite church, joined by their loyalty to living Christ-led lives. This would, effectively, separate them from the world and require rejecting all instruments of the state, including the sword. Violence, particularly as a tool for enforcing the resolve of church life, was considered in direct contradiction to the teachings of Christ (Dyck 1993:106). In other words, Anabaptists established themselves as flagrantly pacifist, a designation that remains to this day. This branded early Mennonites as adversaries of established church structures and enemies of the state; as many as 2,500 followers were killed or executed by state decree up to the last official martyr in the 1570s (Dyck 1993:110). After this period of martyrdom, Mennonites and other Anabaptists continued to face persecution as a direct or near-direct result of their formation as a social movement centered around a non-violent commitment to the biblical preaching of Jesus calling followers to put down arms, feed the poor, give up possessions, and love your neighbor.²⁶ Anabaptists have endured state-sanctioned execution, property destruction, ethnic cleansing, and public persecution of various levels based on their non-state religion and their refusal to take up arms at virtually every point of military conquest or state-church conflict in their geographies.²⁷ This stance vis-à-vis the state is still a major driver of Amish decisions to decline participation in many state-related activities, nationalistic rhetoric, or anything deemed too influenced by the knowledge of man. Theirs is an empire of God built on the humble teachings of Christ.

In the early 17th century, Swiss officials continued to drive Mennonites out of

²⁶ Historical and modern Anabaptists place a primary theological focus on these passages—mostly coming from what is known as the Sermon on the Mount (Matthew 5) and the Agony / Arrest in the Garden (Matthew 26).

²⁷ Open any chronological history of an Anabaptist group and these landmarks are easy to find. The handful I mention here are just an excerpt—virtually any major military action or periods of state-church sanctioned clash saw conflict with the basic tenants of Anabaptist faith. For example, in Nolt's excellent *A History of the Amish*, (1992) each era is touched on in turn as points of history where Anabaptists come up against state forces. Just to choose some of the larger ones: politically-ordered deaths and imprisonments in the early 17th century (19,24), Napoleonic campaigns (78-82), the American Revolution (70-74), the first World war (225-228).

Switzerland. But an end to the Thirty Years War found these communities with reputations for agrarian success with a number of invitations to farm lands in the Palatinate and the Alsace regions of the Rhine river valley (Nolt 1992:20). During this era, Mennonites continued facing disagreement from outside, inside, and around their church organization. On the margin between believing, insider participants and non-believing, political persecutors were those individuals who were sympathetic to the plight of the Anabaptist but not members of the church. Given tight-knit communities, particularly in Switzerland, these were close friends and even extended family members of those being harshly victimized by the state. Such amicable individuals were referred to as the True-Hearted—*treuherzige*—and controversy soon arose within Anabaptist circles about how best to deal with their True-Hearted neighbors (Nolt 1992:24-26). On the one hand, it would be in keeping with the church's message to accept the love of kind neighbors, pray for their salvation, and continue relationships with them knowing that God would decide on those souls in the end. On the other hand, Anabaptist tradition outlined a firm separation between the church and the world; Mennonites should not depend on non-believers. Even more so, if those True-Hearted were previously baptized but returned to the state-run church, these should be held to excommunication and possibly social shunning (Nolt 1992:25-26). This later view was most popular in the Alsace and Palatinate regions.²⁸

In 1632, Anabaptist leaders generated a long-standing confession of faith referred to as the Dordrecht Confession²⁹. This document outlines eighteen articles of faith and has been used in official church doctrine or as religious guidance by various Anabaptist groups well into the

²⁸ Nolt (1992) suggests this geographical leaning was due to the fact that Anabaptists in the Alsace and Palatinate, being more recent immigrants, were less likely to have a number of familial connections to the True-Hearted. It may have been easier for these groups to stand behind the idea of strict social shunning.

²⁹ The entry entitled “Dordrecht Confession of Faith (Mennonite, 1632)” on GAMEO outlines and references the original documents and historical translations of the confession, as well as offering a full English translation. See [http://gameo.org/index.php?title=Dordrecht_Confession_of_Faith_\(Mennonite,_1632\)](http://gameo.org/index.php?title=Dordrecht_Confession_of_Faith_(Mennonite,_1632))

21st century. In this era of dispute around treatment of the True-Hearted, the Alsatian and Palatinate Anabaptists turned to the Dordrecht Confession. Emphasis on the eleventh (foot-washing) and seventeenth³⁰ (social shunning) articles stood in contrast to their Swiss Brethren, who never fully took up either of these practices (Hostetler 1993:33-35). Both groups would have recognized excommunication as an important church practice as outlined in the earlier Schleithem Confession³¹. Compounding this punishment with a full social ban—or *Meidung*—as called for in the seventeenth article of the Dordrecht Confession was not something the Swiss Brethren fully stood behind. In comparison to the major theological and socio-religious reformations of the day, these kind of disagreements may fall into the class of “family squabble,” (Hostetler 1993:33) but they led to a schism among these regional Mennonite churches resulting the genesis of the Amish sect and their subsequent further separation from the larger society.

³⁰ Seventeenth article entitled “Of Shunning the Separated,” translated from the Dutch to English by Joseph Sohm and reproduced in *Martyrs Mirror: The Story of Seventeen Centuries of Christian Martyrdom From the Time of Christ to A.D. 1660* (Van Bragt 1938):

Concerning the withdrawing from, or shunning the separated, we believe and confess, that if any one, either through his wicked life or perverted doctrine, has so far fallen that he is separated from God, and, consequently, also separated and punished by the church, the same must, according to the doctrine of Christ and His apostles, be shunned, without distinction, by all the fellow members of the church, especially those to whom it is known, in eating, drinking, and other similar intercourse, and no company be had with him that they may not become contaminated by intercourse with him, nor made partakers of his sins; but that the sinner may be made ashamed, pricked in his heart, and convicted in his conscience, unto his reformation.

Yet, in shunning as well as in reproof, such moderation and Christian discretion must be used, that it may conduce, not to the destruction, but to the reformation of the sinner. For, if he is needy, hungry, thirsty, naked, sick, or in any other distress, we are in duty bound, necessity requiring it, according to love and the doctrine of Christ and His apostles, to render him aid and assistance; otherwise, shunning would in this case tend more to destruction than to reformation.

Therefore, we must not count them as enemies, but admonish them as brethren, that thereby they may be brought to a knowledge of and to repentance and sorrow for their sins, so that they may become reconciled to God, and consequently be received again into the church, and that love may continue with them, according as is proper.

³¹ The translated text of the second article, concerning excommunication, follows. This version was translated by John Howard Yoder; commentary and link to full text can be found here: Schleithem Confession (Anabaptist, 1527). Global Anabaptist Mennonite Encyclopedia Online. http://gameo.org/index.php?title=Schleithem_Confession.

We have been united as follows concerning the ban. The ban shall be employed with all those who have given themselves over to the Lord, to walk after Him in His commandments; those who have been baptized into the one body of Christ, and let themselves be called brothers or sisters, and still somehow slip and fall into error and sin, being inadvertently overtaken. The same be warned twice privately and the third time be publicly admonished before the entire congregation according to the command of Christ (Matthew 18). But this shall be done according to the ordering of the Spirit of God before the breaking of bread so that we may all in one spirit and in one love break and eat from one bread and drink from one cup.

Among those moving north to the Alsace from Switzerland, a man called Jakob Ammann relocated to serve as an elder to a congregation in what was then referred to as Markkirch³² (Nolt 1992:34). The historical record remains sparse in regards to his biography³³; the majority of what we know about him comes through correspondences penned proximate to the split in the Mennonite church. Change began when Ammann instituted communion as a twice-yearly practice instead of the traditional once a year. If nothing else, this placed churches in the position of having to agree or disagree with this young leader's change. While more senior church leaders, most notably Hans Reist, were not adamantly against the idea, they did not deem it at all necessary. Ammann soon moved on to insisting that Mennonite churches embrace two aforementioned practices outlined in the Dordrecht Confession: *Meidung*—the strict social shunning of the excommunicated, and foot washing as a regular congregational practice signifying servitude to the church as outlined in the New Testament.³⁴ It seems as though churches in Alsace were following these trends under his influence and their commitment to the Dordrecht Confession. But the Swiss churches had not committed themselves to these alterations in church practice, so Ammann and three ministers from Alsatian congregations took a trip south and held meetings with church leaders in order to demand they state absolute positions on three issues: the use of *Meidung*, if the True Hearted would be saved by God, and if lying was grounds for excommunication. Congregational heads varied in their answers; Hans Reist notably rejected the use of *Meidung* outright, claiming that Christ also socialized and ate with sinners (Mast 1950

³² This German name is likely how the town was referred to at that time; it corresponds to current-day Sainte-Marie-aux-Mines.

³³ Hostetler (1993:43-49) gives a comprehensive summary of the research on Ammann's identity including the two best possibilities from birth records that may be a match and research on his signature.

³⁴ From the footwashing described in John 13:3-17 (NSRV); this section begins with Jesus washing the feet of his disciples and end with this call for them to do the same:

So if I, your Lord and Teacher, have washed your feet, you also ought to wash one another's feet. For I have set you an example, that you also should do as I have done to you. Very truly, I tell you, servants are not greater than their master, nor are messengers greater than the one who sent them. If you know these things, you are blessed if you do them.

in Hostetler 1993). Given the variety of responses to his demands, Ammann called for a joint meeting of all the area ministers. The short notice kept some away; others were repelled by Ammann's bullishness and requested time to review these matters with their whole congregations in standing with Anabaptist tradition. Reist claimed to be too busy with the harvest to attend a meeting and directed others to not be swayed by the movements of "younger men" (Mast 1950 in Hostetler 1993).

Ammann was so incensed at being rebuffed that he drastically and dramatically excommunicated six of the Swiss ministers on the spot. The account includes women weeping, men begging to be heard, and Ammann's party storming out in anger. In the aftermath, he sent out a letter to the Swiss ministers demanding they align with him by March 7, 1693. Their Mennonite Brethren in the Palatinate met soon after to discuss which side they agreed with. Being unable to come to terms with Ammann's demands, Ammann excommunicated many of them too, thus solidifying a real schism in the Swiss-German Mennonite world. Sixty-nine ministers from across these regions took sides in the argument—twenty-seven, mostly from the Alsace, sided with Ammann (Hostetler 1993:38).³⁵ From there, Ammann's followers were known as the Amish or the Amish Mennonites.³⁶ Ammann also began to stress simple clothing and the avoidance of anything materially fashionable, including trends in beard cutting or hairstyles. This further emphasized separateness from both the Swiss Mennonites and from the larger Swiss-German context. Hostetler (1993:39) notes that hooks-and-eyes were not originally part of

³⁵ Given the Mennonite penchant for forgiveness and peace building, there was a somewhat ironic twist to this story in 1700 when Ammann and his followers admitted they had acted rashly and without the consent of their congregations. At this point, they returned to the Reist group and proceeded to openly excommunicate themselves in an act of public humiliation and ask for forgiveness from the Mennonite Church. The rift was too deep at that point and the Mennonite leaders could not forgive; instead, they shunned the new Amish, effectively using their own harsh policies against them. See (Hostetler 1993:38-39, Nolt 1992:37-38).

³⁶ Likely a borrowing from Ammann's name—this explanation is confirmed in oral histories but complicated by the variety of spellings coming down through written records. However, it was common in Swiss dialects at that time to shorten surnames by adding a diminutive "i", thus, "Ammi-" combined with the German suffix "isch" creating "Ammisch." (Luthy 1978:5).

Ammann's strictures but they later became a symbol of this kind of material constraint when the Amish became known as *Häftler* (hookers) and the Mennonites as *Knöpfler* (buttoners). This designation became an emblem of their differences and many Amish affiliations to this day refrain from the use of button closures and opt to use hooks-and-eyes, snaps, or straight pins to fasten articles of clothing and head coverings.

Migration

The 18th century saw a large number of people pushed out of the Rhine river valley due to rising taxes, poor economic conditions, and unstable political atmospheres. For the Amish, prevailing religious intolerance and their own resistance to military training compounded this momentum. Some families were migrating to other parts of Europe on their own, many heading to French-speaking areas. Swiss intolerance ruled the day and the government in Bern began to actively expel the Amish around the turn of the 18th century; soon there would be only three congregations left in Swiss territories and a handful in the Alsace. After a failed attempt contracting the Dutch East India Company to literally ship all Anabaptists out to islands in the Pacific, political figures eventually planned to use their own resources to ship them to North America. In 1709, the government in Bern contracted a ship company to take a boat full of Anabaptists to the Carolina colonies in the New World, but officials in the Netherlands would not give the ship clearance holding passengers detained against their will (Hostetler 1993:53). A few years later, the Netherlands offered asylum and safe passage into Dutch territories where Anabaptists could eventually make their own decisions about where to relocate. Due to their inimical history, many Mennonites refused to be displaced alongside the Amish, jumped ship along the way, or returned upon arrival, so the parties arriving in the Netherlands aboard

contracted ships were almost entirely Amish. They were a bit of an alien novelty in Dutch territories; their language, untrimmed hair, and plain dress was bizarre (Nolt 1992:45-52). Amish endurance as a church-driven social movement in this era is notable. Held together by community-dictated guidelines and reinforced by cohesion in the face of outside persecution, Amish cultural worlds began to gel in practice. Remarkably, this foray into otherness foreshadows the eventual, perpetual outsider gaze fixed on the Amish in current day North America.

Amish and Mennonite groups continued to move to pockets in Europe and even enjoyed a brief period of invitation to farm in Bavaria. Migration took Amish well into Polish territories and as far eastward as Russian Volhynia. It has been suggested that social and political acceptance, such as that in the republican phase of post-revolution France, encouraged some Amish churches to let down their religious barriers and invigorated assimilation with Mennonites and other cultural groups.³⁷ However, many of these newly opened avenues for social and political acceptance were thwarted during the Napoleonic era due to Anabaptist dedication to pacifism (Nolt 1992:50, 77). Slowly, Amish congregations across Europe dwindled due to migration to the New World, continued difficulties in Europe and Russia, and a gradual assimilation with Mennonites. A handful of congregations held on well into the 20th century. The last Amish congregation in Europe, located in the Palatinate, merged with a local Mennonite congregation on January 17, 1937 (Nolt 1992:183).

William Penn also came from a persecuted historical peace church in Europe, and his new Pennsylvania became a sanctuary not only for his fellow Quakers, but also these other

³⁷ For full history of French Anabaptists, see: Séguy Jean. 1977. *Les Assemblées Anabaptistes-Mennonites de France*. Mouton & Co, Paris et La Haye. Also, a translated work: Séguy, Jean. 1984. "The French Anabaptists: Four and One Half Centuries of History." *Mennonite Quarterly Review* 58 July:206-217.

religious minorities fleeing from Europe (Nolt 1992:48). By the end of the 18th century around 500 Amish people had emigrated³⁸. One of the earliest settlements formed in Berks County, Pennsylvania, and soon after, some Amish moved into the Conestoga area of Lancaster County (Nolt 1992:56). Many Mennonites had arrived earlier, bought unimproved land, and developed the richest soils in and around Lancaster County. The Amish were left with buying frontier land or already-improved farms from other individuals. This left the colonial Amish buying in areas of Berks, Lebanon, Mifflin, and Chester Counties (Nolt 1992:59-60). In many ways, these small Amish enclaves held a lot of similarities with their other colonial neighbors—they worked hard in rugged conditions to reap the benefits offered by Penn’s offer of religious freedom. At the same time, the Amish differed from their neighbors in a number of ways: a distinct dialect of low-German³⁹, relatively plain dress, unshorn beards, refusal to own slaves, and attempts to live with non-resistance on borders with native peoples (Nolt 1992:65-67).

Life for the Amish in early America was scrappy at best. Their numbers dwindled as some were attracted to join in worship with neighboring church groups such as the Church of the Brethren, some were swept up in Methodist revivals, and others simply found their children leaving to marry outside of the church (Hostetler 1993:63). Families were scattered over a number of Pennsylvania counties. Of those who stayed in the church, many were socially persecuted, harassed, or harmed in their refusal to fight in the American Revolution. For example, in the long-standing tradition among Anabaptists and Quakers of refusal to take oaths, they declined and petitioned the Oath of Renunciation and Allegiance (Hostetler 1993:64). While

³⁸ October 1737 is often cited as the date when the Amish first landed in America but it is likely that some had already arrived. This marks the Philadelphia docking of the *Charming Nancy* after its journey from Rotterdam; the ship contained a large number of Amish families.

³⁹ Known usually as Pennsylvania German, or Pennsylvania Dutch, this remains the first and primary language of the current-day Lancaster Amish. Modern Amish are fluent or near-fluent in three languages: Pennsylvania German, High German, and English.

their declination was largely based on living in commitment to the Kingdom of God, not of Man, this was seen as an act of allegiance to the British crown. At the same time, their refusal to take up arms was seen as an act of revolutionary defiance. The religiously led pacifists of this era⁴⁰ were often rendered as enemies to all and the colonial Amish did not enjoy the social strength of a large settlement. For their first century in the New World, pockets of Amish families were clustered together in and around Mifflin, Somerset, Chester, Berks, and Lancaster counties; in addition to pressures to commit to violence, Hostetler (1993) notes that these were small groups pushed upon both by other outside social pressures and issues of finding good land. All of these factors led to a tumultuous century of trial-and-error community building for the Pennsylvania Amish.

This began to change when the Lancaster settlement set up as a proper division in 1843. Only then could it ordain its own Bishops. The move from family-based, outspread pockets joined only by a single traveling Bishop to a demarcated settlement within a single geography was significant in the formation of cultural identity among Amish in the area and resulted in two substantial impacts on participation and practice. First, as the settlement brought together founders, familial control over socio-spiritual practice was relinquished and picked up by the church as a singular body. People further let go of personal stakes and individual identities in favor of expressing a mutual idea of what it was to be Amish via community rules of order. Second, as these elements of what it meant to be Amish began to be worked out in practice, the

⁴⁰ This was the case as well during the wars to come in subsequent centuries. For example, during the American Civil War the Amish refused to enlist, did not allow members to participate in any sort of work under military control, and former members who fought and wanted to be reinstated to the church were required to refuse their government pensions (Hostetler 1993:280). Many Anabaptists changed their approach to objection by the Second World War and were willing to participate in non-violent service positions, Many took up service in the recently-formed Mennonite Central Committee (MCC). MCC still operates as a non-messianic (but religious) NGO focused on relief work and peace building worldwide (<http://www.mcc.org>).

settlement stepped further to demarcate itself from the English (non-Amish⁴¹). This resulted in both internal and external disagreements and forced some Amish to relocate themselves in various settlements according degrees of community discipline (Hostetler 1993:65). These two elements of Amish practice—a sense of strict communal identity as followers of Christ here on earth and an idea that they should remain separate from worldliness—became touchstones of what it means to act as Amish in contemporary society.

In the second wave of Amish emigration during the 19th century, many newly-arrived, European Amish found the Lancaster settlement to be too conservative and choose either to convert their churches to Mennonite congregations or to locate further north or west, particularly in Ontario and Indiana. These internal struggles continued through the 19th century for all American Amish, eventually resulting in a gradual split into Old Order Amish and Amish Mennonite churches⁴². This left a founding population in Lancaster formed by a handful of families present before and right around the formal settlement distinction. Prominent histories of the Lancaster Amish gloss over details of exactly who the founding members of the settlement were. The Stoltzfus family gets commonly mentioned for good reason—their surname has been

⁴¹ “English,” is the Amish way of referring to those who are not-Amish. This is usually understood to be in reference to non-Amish being native English speakers as opposed to Pennsylvania German speakers. The designation, however, has come to encompass any non-Amish individual. There is a bit of a grey area along the Anabaptist spectrum—some Plain are referred to by their sect or group names instead of falling into the “English” category. For example, the Team Mennonites or the New Order Amish are often referred to using these affiliation names. All other non-Plain people, including progressive Mennonites, fall into the category “English.” Many Amish would refer to Spanish speakers or other immigrants in and around their community as English, although they may designate non-white individuals into other categories. An immigrant from South America working alongside Amish laborers on a construction job may be referred to as “English” (non-Amish) and given another designation such as “Mexican” (a category I heard often to include any Spanish speakers). Note that the term English will be used throughout this work to refer to the non-Amish.

⁴² Nolt covers this era well in his 7th chapter of *A History of The Amish* (1992:125-154). This included nearly-annual ministers meetings over the course of 15 years where groups of deacons, bishops, ministers, and laypeople from all corners of the Amish world came to debate in a moderated forum. The conservative congregations and the “change-minded” progressives met to hash out a myriad of particulars, from individual dress to community ownership. Nolt notes that these meetings seemed to drive-apart more than they joined-together, eventually resulting in the structural split by the Amish Mennonites (formerly the “change minded”). The Amish Mennonites further subdivided during this time. Other affiliations have continued to splinter from the Old Order well into the 20th century.

reproduced as the most commonly occurring name among the Old Order Lancaster Amish today. Similarly, close genealogies kept by the Fisher (Beiler 2009) and King (Hartzler 1984) families offer important compilations of genealogies. Beiler's book, published locally in the Lancaster area, is referred to as *The Fisher Book*⁴³ by Lancaster Amish and is commonly found in Amish homes across the settlement today. The most recent update contains over 50,000 individuals spanning across the history of the area. The first record of this lineage, Ulrich Fisher, came to Pennsylvania in 1732, but it was not until the 1790s that there seems to be a move of the family into Lancaster County. The genealogy starts in earnest with Christian Fisher as the first numbered entry and his daughter, Barbara Fisher, as the second. Barbara married a John King; her entry notes that the Kings are "so numerous intermarried to the Fisher family," their genesis in the line must be mentioned. Not surprisingly, King is the second most common surname among the Lancaster area Amish⁴⁴. Samuel Koenig (King) is noted to have sailed to Pennsylvania in 1744. He eventually had 14 children, but most of his direct line gets expanded in the King Family History—although the intertwinings with Fishers, Beilers, Stoltzfuses, and others are numerous from the outset. Simply a glance over the first few entries of the Fisher book unearths the surnames rampant in Lancaster County today among the Amish as well as Amish in other areas and Mennonite groups both conservative and liberal: Stoltzfus, King, Fisher, Beiler, Zook, Sauder, Lapp, Schmucker, Peachy, Detweiler, Yoder, Petersheim, Kauffman, among others. These get reiterated in a dizzying array of combinations made no simpler by the constant repetition of common first names. These early families were the *founders* of Lancaster's

⁴³ While not the official title, *The Fisher Book* is referenced this way consistently (and frequently) by consultants, both Amish and English, in the field. A copy of the book can be found in many homes and as a visitor or friend with any historical connection to the Amish, it's common to be asked, "Are you in the Fisher Book?"

⁴⁴ Unpublished surname frequencies from the Young Center for Anabaptist and Pietist studies put the King at 12.04% and Stoltzfus (combined spellings) at 26.76%.

extant Old Order Amish population—a label with historical, cultural, and genetic implications for an endogamous community in an ever-modernizing world.

After the Lancaster settlement solidified, North American Amish groups experienced cleavage a number of times as church members disagreed on a wide array of socio-religious practices. Two of the largest subdivisions in Pennsylvania did not occur until well into 20th century—the Beachy Amish, in 1927, and the New Order Amish, in 1966. These Amish affiliations continued to endure in some form around Lancaster County but eventually lost footing. Unlike the largest settlement in Ohio, containing eleven affiliations in one area, the Lancaster area settlement is now comprised almost entirely of Old Order Amish. Scholars include varied affiliations in their number of tallied “Amish” writ large, but use the metric of horse-and-buggy travel plus Amish self-identification as a designation. In other words, New Order and Old Order Amish utilize horse-and-buggy travel but the Beachy and Amish Mennonites are not included because they allow members to own and/or drive cars. At the same time, there are horse-and-buggy Mennonite groups living in the same county but they are not counted because they do not self-identify as Amish. Under these guidelines, the Lancaster settlement in 2012 held a total population of 31,020⁴⁵ people in its 188 church districts. Due to the population density of the area in comparison to other Amish-heavy regions, the Lancaster settlement has more people-per-district, or *Gmay*, than any of the other big settlements—165 people per district. Although the largest settlement, the Holmes county area of Ohio, weighs in with a whopping 246 districts, it actually holds a district average of only 130 and therefore only a

⁴⁵ Population figures are tabulated by scholars at the Young Center for Anabaptists and Pietist Studies and involve a combination of migration reports from district averages, the Amish newspaper *The Diary*, other correspondances in Amish print publications, Rabers Almanac, the official settlement directories, and Amish informants. For this settlement data see: “The Twelve Largest Amish Settlements (2012).” Young Center for Anabaptist and Pietist Studies, Elizabethtown College. http://www2.etown.edu/amishstudies/Largest_Settlements_2012.asp.

few hundred more individuals than Lancaster.⁴⁶

Members of a *Gmay*, along with their children, worship together. The average church-size in the Lancaster area is 165 people. The Amish do not use church buildings or specialized meeting places. Worship occurs every other Sunday at the home of a family in the district and rotates among everyone with the space to accommodate the whole group. The off-Sundays are used mostly for short trips within or outside the district for visiting others. The church schedule varies from district to district and is set by the local bishop. Although the boundaries of a district are determined geographically and typically break at natural borders, their size often depends on the number of members able to worship together and the distance required for those members to travel by team⁴⁷ throughout the district. When the size of a district becomes too large to comfortably meet together, they will split.

Cultural Worlds and Horizons of Meaning

With no governing body and no centralized regulatory structures, what it means to *be* Amish is necessarily tied to the practices and discourses that are learned, dictated, and shaped at the district level. As suggested in Chapter 1, the boundaries of a district are many things—physical, social, flexible, resistant. The *Gmay* is the community of practice where group identity is constantly formed, fortified, and enforced. The directness of governance and self-sufficiency of these communities of practice, backed up by persuasive discourses of faith, serve to minimize the autonomy of individuals in favor of group practice. The Amish do not remain separate and

⁴⁶ A number of major works record historical developments, social structures, and customs among various Plain communities (Horst 2000, Hostetler 1980, Nolt 1992, Weaver-Zercher 2004). Additionally, more focused analytical works have been produced addressing practices and regulations in Amish communities (Foster 1984, Gallagher 1981, Kraybill 1989, Nolt and Meyers 2007, Kraybill et al. 2013) as well as examinations of Amish work in economic, educational, or other venues (Huntington 1994, Johnson-Weiner 2006, Kraybill and Nolt 2004, Umble and Weaver-Zercher 2008).

⁴⁷ Team refers to horse-and-buggy travel

distinct by simply demanding conformity from a top-down chain of theological edicts. Their interactions with one another and with the world are imbued with a distinct set of meanings and these meanings both shape and are shaped by Amish group identity. I contend that this group identity forms the frontline for interacting with the world, both within and outside their communities of practice⁴⁸. In other words, these cultural worlds produced and performed by the districts are populated by actors engaging in limited ranges of “meaningful acts or changes of state as moved by a specific set of forces” (Holland et al. 1998). Through membership and presence in the *Gmay* practice, collections of Amish individuals form senses of self in the cultural world and develop identities in conjunction with their participation. This participation is both relative to and generative of actors’ agency as well as their embodiment of activities, acts, and outcomes bounded by such a world.

Involvement in a religious sect with group-enforced social rules that are in great contrast to the larger cultural milieu involves authoring collectively produced horizons of meaning against which action is interpreted. The ongoing production and embrace of collective identity among a group of actors occurs in the process of their joint activities and commitments. Nonetheless, despite the importance of the resulting cultural world for the individual’s sense of self, the existence of the individual cannot be disregarded. This is where the Amish case is soon troublesome to the usual understandings of the relationship between collective and individual. As actors’ identities are built in the realms of Amish practice, the practice itself dictates that actors fold their individual identities back into the whole—a true lamination of the self to the social identity of the Amish person *for the self*. Amish practice itself persistently pushes toward two horizons of meaning: the trussing of community via the *yielding of individual selfhood* and that

⁴⁸ This is, perhaps, the seed of truth at the heart of Amish homogeneity stereotypes. Members of Amish communities (and other Plain groups) often appear as a singular type because their cultural practices tend to produce that appearance as a byproduct.

community's *separation from the surrounding world*. I refer to these joint horizons as ***Amish mutual separation***. I will continue to use this term throughout to refer to the joint interests of separation from outside and cohesion from within.

And its result is a collective identity that minimizes the autonomy of individuals while maximizing their difference from non-Amish. To understand how this social participation in Amish cultural worlds impacts agency as individuals encounter difference, I must first establish the bounds and influence of the cultural world created in Amish communities of practice and then look to how those bear upon personhood. The rest of this chapter will focus on the first of these tasks; the second will be picked up again in chapter six. The community of practice performs a cultural world in which “living in a redemptive community, separated from the world, is essential to salvation” (Hostetler 1993:22). Indeed, parsing this quote reveals the two guiding concepts that underlie the cohesion of Amish mutual separation: (1) the concept of *Gelassenheit* binds together a redemptive community under *Ordnung* able to (2) exercise separation from worldliness. Let me address these in turn.

Amish mutual separation: *Gelassenheit und Ordnung*

Variouly described as silence of the soul, inner surrender, conquest of selfishness, equanimity, resignation (Hostetler 1993), *Gelassenheit* may be best captured as a call to adherents to yield their personal interests to Christ and the church community. This *uffgevva*, or “giving up,” in the spirit of *Gelassenheit* aims to create generalized placidity and avoid situations of social inequity. This active eschewing of individualism by stringently enforcing *Gelassenheit* results in a relinquishing of self-will for the benefit of community. Subsequently, Amish collective identity can be understood then as resting upon the “yielded self” (Kraybill 1989); or

more appropriately, upon an assemblage of yielded selves. As a singular Amish person dedicates him or herself more stalwartly to the concept, the greater that individual may meld, or be laminated, into a collective Amish.

Gelassenheit is a vital concept, and one most overlooked in the popular understanding of the Amish. Among other things, the spirit of *Gelassenheit* gives meaning to the refusal to own or drive cars; the spirit of *Gelassenheit* maintains the use of plain dress and aesthetic conformity; the spirit of *Gelassenheit* undergirds gender and kinship expectations in the community. A reflection of general Anabaptist tradition, Amish theological meaning of such everyday practice comes from judging biblical Gospel and Apostolic teachings as superior to rules and teachings of the state or social system in power. Indeed, the death of Jesus, interpreted literally in the community, is seen as an exemplary act of *uffgevva*.

Sacrifices in the spirit of *Gelassenheit* likewise couples with New Testament teachings that motivate the Amish quest to separate from the world:

“Do not be conformed to this world, but be transformed by the renewing of your minds, so that you may discern what is the will of God—what is good and acceptable and perfect.”⁴⁹

Notice here that the focus is on living, not on being saved in death. The Amish certainly believe that they may attain salvation beyond this lifetime. But a spiritual believer should focus her actions through a life of belonging in the redemptive community; navigating this world is an act of faith and an opportunity to live righteously. Amish theology receives an apt description in Kraybill, et al. *The Amish Way: Patient Faith in a Perilous World* (2010). The Amish way does not focus on eschatology or dwell on revelation; instead, their Anabaptist history shines through the day-to-day practice of living Christ-centered lives of sacrifice, pacifism, community, and

⁴⁹ (Rom.2:12 NSRV)

uffgevva.

“Do not love the world or the things in the world. The love of the Father is not in those who love the world; for all that is in the world—the desire of the flesh, the desire of the eyes, the pride in riches—comes not from the Father but from the world. And the world and its desire are passing away, but those who do the will of God live for ever” (1John 2:15-17 NRSV).

Amish ideas of worldliness are defined by Hostetler as threefold: seeking comforts, the love of material things, and self-enhancing activity (1993:22). *Gelassenheit* coupled with separation from the flows of English culture become the symbiotic horizons of meaning regarding Amish mutual separation.

To achieve this, Amish communities dialogue in a unique social grammar dictated by the *Ordnung*—order, or “community rules of order”. In many ways, the *Ordnung* operationalizes the concept of *Gelassenheit* among Amish church districts and provides the boundaries for separation from worldliness by way of defining limits on comforts, material goods, and self-enhancing personal activity. Each *Gmay* determines its own rules of order under supervision, but not control, of the bishop. Almost always maintained as an oral document in the community,⁵⁰ the *Ordnung* gets reviewed or altered in the context of the liturgical calendar. Descending from Jakob Ammann’s switch to twice-yearly communion, Amish districts continue to practice the Eucharist once in the spring, near Easter, and once in the fall. These are the most important and revered days of the liturgical year and a district will spend the five preceding Sundays preparing for the practice⁵¹. It is not uncommon in Anabaptist churches, even in progressive and liberal congregations, for the ritual of communion to be a time for community reconciliation and an

⁵⁰ Kraybill, et al. (2010) gives an excerpt about buggy making in an Indiana *Gmay* from a rare written *Ordnung* (54-55). They note that this is an unusual medium.

⁵¹ See Kraybill, et al. (2010:69-74) for a detailed description of the preparation for the Eucharist and what happens on the day-long ritual of communion Sunday.

opportunity to make relationships with church members clean again⁵². This takes the emphasis off of personal salvation and places it back into community cohesion as a path toward righteousness. As part of this lead-in to communion, the *Gmay* holds a council meeting—an altered service sometimes referred to as *Ordnungsgeme*. This service is for baptized adults only, men and women, as all members examine the practices of the church and their personal indiscretions. Although men hold positions to exercise greater power, women get equal votes in the consensus processes of decision-making and community reconciliation⁵³.

These council meetings begin with the bishop preaching the entire biblical story from Genesis, through the prophecies, through the life and death of Jesus. He then moves into the *Abstellung*—the putting away or placing off-limits⁵⁴. Just as any member must be at peace with one another to receive communion, the *Gmay* as a whole must be at peace with its own restrictions and community practices before they will approach the Lord’s Table⁵⁵. The *Ordnungsgeme* provides a space where these communities of practice knowingly and actively

⁵² This tradition takes different forms in various Anabaptist congregations but usually involves confessing of sin and full reconciliation between any two members of the community who feel wronged in any way. In Amish churches, communion Sunday will even be postponed if disagreements remain between members or sinful behavior has not been confessed. The focus of communion as a community practice is covered explicitly in the third article of the 1527 Schleitheim Confession (emphasis added):

III. Concerning the breaking of bread, we have become one and agree thus: all those who desire to break the one bread in remembrance of the broken body of Christ and all those who wish to drink of one drink in remembrance of the shed blood of Christ, *they must beforehand be united in the one body of Christ, that is the congregation of God*, whose head is Christ, and that by baptism. For as Paul indicates, we cannot be partakers at the same time of the table of the Lord and the table of devils ... So it shall and must be, that whoever does not share the calling of the one God to one faith, to one baptism, to one spirit, to *one body together with all the children of God, may not be made one loaf together with them*, as must be true if one wishes truly to break bread according to the command of Christ.

⁵³ Kraybill et al. put an interesting point on this with two opposing quotes from Amish informants. One, a woman, notes that women are absolutely free to participate, speak and be listened to in church meetings. Another informant, a man, says too much of this may border on women “being out of their place” and should suggest women maintain their influence privately by using their husbands as (unwitting?) proxies (2013:202).

⁵⁴ Translation from Kraybill, et al. 2010: 70

⁵⁵ This common euphemism for the rite of holy communion in Christian churches comes from the ritual’s roots as a reenactment of the biblical story when Jesus shares a last supper with his disciples before capture. In the biblical recounts of this supper, Jesus commands that when his disciples break bread and drink wine, they do so in remembrance of him. Anabaptist churches also place special value on the foot washing performed at the last supper and recreate this as ritual on a regular basis. Amish participate in a foot washing at every communion.

alter the shape of their cultural worlds by deciding the conformities of their day-to-day practice—twice a year they raise up inconsistencies in their communal practices and reaffirm the *Ordnung*, smoothing down the edges of autonomy and re-laminating the community.

What does the *Ordnung* specify? If the cultural world is shaped by the horizons of meaning given by Amish mutual separation, the *Ordnung* details what is created and what is separated. The *Gmay* comes together through members' separation from the world; Hostetler notes that they must then settle on how the community must be separate for the true "body of Christ must be 'of one mind.'" Oral tradition, formally ratified in six-month intervals, holds up *das alt Gebrauch*—the old way—as the best option for mindfully navigating full community cohesion through separation (Hostetler 1993:83). As an addition to biblical teachings, the district decides its limitations on the use of various technologies, what kind of clothing should be worn, hairstyles, educational standards, acceptable vocational practices, and the like. There are commonalities across districts and settlements—things that seem to hang together as commonly-Amish—no tapping into the electrical grid⁵⁶, horse and buggy transportation, no telephones inside the home⁵⁷, plain dress, unshorn hair for women and beards for men. Each district will enforce these and then add additional layers of detail or nuance.

Technology and space: negotiation of change

This provides a good segue into discussing technology. I've established how the Amish coordinate their interactions in communities of practice to create and perform figured worlds

⁵⁶ Note that this is more specific than simply saying no electricity. Many Amish, and particularly the more wealthy and progressive Amish of the Lancaster area, use electrical devices that derive that power from diesel generators, solar power, or batteries that have been charged using inverters.

⁵⁷ For a full history of the Old Order Amish and the use of telephones, see (Umble 1996). For a recent update, including the use of cellular telephones, see (Kraybill et al. 2013:323-324)

deriving from religious and social meanings maintained by their internal actors. Amish mutual separation folds together two horizons of meaning: the cohesion of a small community characterized by the renunciation of self-will and the thoughtful separation of the community from the surrounding world. Such a separation, of course, involves interactions that flow between a segregated Amish and an English reality. Amish, particularly in the Lancaster area, constantly engage in social, economic, political, and spatial exchange with other social actors outside of Amish communities. That exchange can be well highlighted by an enduring negotiation with technological change and the cultural artifacts that come along with that slow negotiation. Material artifacts play a dominant role in the cohesion of Amish group identity; they also mediate the flows between Amish and English worlds.

Examining negotiations of technology provides one of the most fruitful venues for exploring the cultural world of the Amish. These communities are often characterized as stuck in the past, holding onto old ways, and rejecting technologies in the media and popular imagination. Romanticized as living in a simpler time, they are seen as turning their backs on modernity and enforcing a society that exists in suspended time. Arresting technological change and proficiently maintaining cultural standards that have been used for generations creates the appearance of a reality crafted to forever remain in the past. Plain clothing, lack of grid-based electricity, avoidance of contemporary material goods, one-room schoolhouses, and use of horse-powered locomotion all point to the construction of a *history* in which they are choosing to remain, a loose estimation of living at the turn of the 20th century. Any scholarly work about the Amish will quickly attempt to disavow these common misconceptions⁵⁸ and Amish scholars are regularly

⁵⁸ Two of the best large-scale overviews of the Amish are (Kraybill, et al. 2013) and (Hostetler 1993). Virtually every academic book published about the Amish, however, addresses the misconception that they simply reject everything “modern.” Some good examples include (Hurst and McConnell 2010), (Johnson-Weiner 2007), (Kraybill 2001), (Kraybill et al, 2010), (Kraybill and Nolt 2004), (Kraybill and Olshan 1994), (Nolt and Meyers 2007), (Umble 1996).

called upon by the news media to explain Amish practice when it appears either incongruous with English values or inconsistent with perceived Amish rules. Why do we see Amish using weed eaters to edge their gardens? Why can Amish ride in a van but not drive a car? Why would Amish immediately reach out to support the family of the man who killed five Amish girls in the Nickel Mines school shootings? Baffling, perhaps, to outsiders.

Space and proximity drive many Amish decisions regarding acceptable technologies, acquiescing to change, and interacting with the English. As mentioned earlier, the element of physical space becomes an important factor in the formation and endurance of Amish collective identity because the units of that collectivity are formed by the geographical boundaries of a *Gmay*. Decisions about modes of transportation are subordinated to one of the main motives of the cultural world—holding the community together as a cohesive group. The issue is not that cars themselves are too modern or somehow too worldly to align with a spiritual life. The threat dwells around potential effects that car ownership may have on building and maintaining cohesive identity within Amish communities of practice. The car is recognized as an object with significant agency that could drastically influence the shape and space of the cultural world. Similarly, the horse and her buggy are also recognized not as simple tools but seen as actors in the formation of Amish practice.

The team⁵⁹ confers meaning on, as well as materially reins in, the limits of the *Gmay*. Space is often restricted by modern infrastructure designed for cars and the community penned in by the distance that is appropriate for a team to travel. Some Amish are comfortable taking their team into the busy crisscross of one-way streets in downtown Lancaster but many are not. There is little or no team parking and relatively dense car traffic to deal with. Likewise, tourists and

⁵⁹ Team is the common term in English used by Amish to refer to their horse and buggy rig.

locals alike tend to travel very quickly on many of the county highways and roads; unless there is a decent shoulder, it takes a stalwart driver to put his or her family in the lane with fast moving cars. Some places the Amish need to go are very hard to access. The local women's hospital, for example, is nestled in a highly commercial area most reachable from the eastern part of the county by interstate-style bypasses—somewhere buggies would never travel. Similarly, Target or Wal-Mart may be convenient for a few (and accommodating—these and many grocery stores offer covered team parking) but are too far to travel by buggy for others. Other trips to visit family in distant districts or for weddings pose similar problems.

The team also confers meaning by providing separation and conformity. The horse and buggy clearly demarcates the Amish from the English across the senses—the look of the buggy, the feel and smell of the horses, the sound of the hoof beats clopping across pavement and scrape of metal wheels rolling behind. The buggy also, however, demarcates the Amish from other horse and buggy driving groups in the same geographical area. There are Mennonite groups in the Lancaster area that utilize horse and buggy travel such as the Wenger Mennonites and the Stauffer or “Team” Mennonites.⁶⁰ Mennonite buggies are black with a characteristic small rectangular window on the back panel. Lancaster Amish buggies⁶¹, no matter the district, are grey. There are some rare variations on body styles, depending on the needs of the family. For example, a covered buggy with only one front bench and a small uncovered cargo space in the back (like a pick-up bed), a double buggy with a secondary passenger buggy pulled linked and pulled behind the first like a tiny horse-pulled train, or a specially made covered trailer pulled low to the ground behind the primary buggy for someone confined to a wheelchair. These

⁶⁰ For more on Old Order and other team-driving Mennonites, see (Kraybill and Hurd 2006).

⁶¹ Buggy conventions are different from settlement to settlement; the bluish-grey buggy is distinctively Lancaster Amish.

variations are sporadic; most covered buggies are a simple box with two backed-benches, no seatbelts, a sliding door on each side and a hatch that can lift in the back. Some buggy conventions may differ slightly from district to district, dictated by the *ordnung*. Many of these are interior (lining colors, accessory panels). From the exterior, the Amish present a solidly-grey aesthetic front clipping along on four metal wagon wheels.

This group conformity is further bolstered by the production value of buggies in the community; buggies and their accessory parts are manufactured by the Amish for the Amish, using skills that have been virtually lost in the English world. Just as other conventions—such as staying off the electrical grid or refusing participation in the social security program—serve their desire to remain disconnected from unknown (ie. corporate) and known (ie. the state) bodies politic, buggy production and maintenance as well as buggies themselves remain part of the durable web of actants buoying the community. This also preserves the quiet equity among members⁶². Amish have no space for social and economic differences stated by the car. Unlike makes of automobiles, buggies are available in a very small price range and they all look the same. All of these factors around the life of the team reveals a calculation incorporating how far an individual should travel outside of the physical geography of his or her church district relative to the time it takes to perform the journey combined with how slightly the rules of mutual conformity to an Amish cultural identity can be bent. This dynamic is further illustrated on the continuum of what other forms of transportation are acceptable. For example, among the districts in the Lancaster area settlement, the Amish forbid pedal bicycles and only use standing scooters⁶³. A pedal bicycle crosses the lines established for appropriate distance over time in

⁶² The concept of quiet equity is elaborated in Chapter 3.

⁶³ Pedal bicycles are acceptable in some of the other large settlements, including some parts of Indiana where Amish are known for their travel by pedal bicycle. It may be notable that these settlements hold a smaller population density.

districts with the density found around Lancaster; it would allow an individual to travel too far out of bounds from his or her community, with too little effort, too quickly.

There are occasions, of course, as workers and consumers in today's economy when the Amish need to travel further than their teams can take them. As suggested above, trips to big box stores, construction jobs in the city, visits to relatives who have relocated to distant districts or even another settlement, or any number of other chores and commitments may require travel that would be inaccessible or inappropriate with the team. In these instances, the Lancaster Amish simply hire a driver to get them from one place to another.⁶⁴ This mode of transportation is particularly important to consider in light of the Amish interaction with biomedical establishments. Very few physicians make house calls; visits to a clinic or admission to the hospital will mostly likely involve car-travel. There are rare clinics, including the Clinic for Special Children, which intentionally place themselves closer to the densest areas of Plain living. But given its specialty, even CSC pulls patients from all over the surrounding counties and even further into Pennsylvania and New England. On any given day, the parking lot is a mixture of horses waiting with their buggies and drivers doing crosswords in the cab of their vans.

Technology and materiality: craft culture and other cultural artifacts

Technology here is understood as the material implements and implementation of a type of modernity understood as a “process of social separation that fragments and differentiates”

⁶⁴ Hired drivers, sometimes referred to as Amish taxis, have sprung up as a thriving small industry in the Lancaster area. They raise some ire and controversy in the English regulatory world because many have not traditionally registered as official taxi businesses and instead chose to operate as an independent network tied together by their Amish clientele. Due to the relative wealth of the Amish in the Lancaster area, many can afford to hire a driver for weekly or even more frequent errands as well as special occasions such as travelling for a wedding or a vacation. Most drivers employ unmarked, twelve-passenger vans with tinted windows. They provide privacy and space for large Amish cohorts to share a ride or to transfer a large family. They are not inexpensive; typical costs run right at \$1.00 per mile and some charge extra for the time they wait while errands or visits are attended to. Drivers and families form loyal relationships and frequently a driver will have families that s/he serves on a regular basis. The Amish family may hold a regular appointment with the driver for something like errands, but frequently a family contacts the driver by phone to get on the schedule for the week or day ahead.

(Kraybill and Olshan 1994:21)⁶⁵. Marx argues that technology facilitates a loss of self, an alienation that turns human workers into appendages of the machine. Amish arguments against technology invoke a similar concern—technology threatens to split and divide the group into individuals while erasing their separateness from the world of men and consuming individuals in to larger flows of consumer, secular, “modern” culture. This potential erasure entails partial loss of the collective Amish identity of the *Gmay* and subsequent alienation from the world of God. In some ways, just as for Marx, technology’s antithesis is rooted in craft. Craft is traditionally defined as: the work of making by hand according to the standards of a particular community in order to fulfill internal needs (Brunvand 1998). Craft objects not only appeal to and align with the practices of the group, they are produced for utilitarian purposes and require no intercession from the outside (or outsiders). Crafting, therefore, is often understood as the practice of a people—not people, *a people*—who produce un-authored objects⁶⁶. This notion, historically, has bred romanticism for a pastoral history filled with the un-authored crafts of people just like the Amish. Like other forms of modernity, the Lancaster church districts, perhaps more than any other settlement in North America, have managed to negotiate this romanticism in order to maintain their community standards while simultaneously reaping the benefits of a romantic stereotype they so thoroughly embody for outsiders.

In the world of work, and specifically the work of craft, many in the Lancaster Amish settlement have embraced microenterprise as a form of careful cultural agreement between their own historical craft-practices and new alienation by technological machinations. These micro-

⁶⁵ Technology is not represented here as its root in *techne*—a knowledge involved in making, producing, even crafting. Instead, the Amish tie the concept “technology” to an alienating modernity that lacks the faith and safety of a cohesive community.

⁶⁶ This concept of un-authorship contrasts the autonomy of the “artist” as compared to the “craftsman.” Without digressing into the much-discussed craft versus art dichotomy, it is worth noting that just as someone may esteem ownership of a (individually authored) Mies van der Rohe chair or a Frank Lloyd Wright glass mosaic window, there is a high reputation for a piece of furniture, a pasture-raised hen, or a pieced quilt being (group authored) “Amish”.

enterprises—in furniture, quilts, home kitsch, baked goods, and organic farmgoods—allow for economic stability⁶⁷ while not requiring them to yield control of their own time, control over technology, and control over scale. This work means negotiating all of these realms to nourish economic health while still preserving their “cultural soul” (Kraybill and Nolt 2004)⁶⁸. Craft work is, like identity, a simultaneity of historical situation and current practice intermediated by cultural artifacts. As folklorist Henry Glassie noted, craft-practice is the work of ordering experience (1999).

As a woman, I had frequent access to the everyday practices of Amish women—particularly to practices of craft in the home space as well as crafting for the marketplace. In terms of material, these two are intimately linked. Many of the Amish-owned small businesses in the Lancaster area entail products created jointly or solely by women and over 20% of these small businesses are owned by women as well (Kraybill and Nolt 2004:74). Cultural artifacts once (and still) crafted for and in the home are being exported from Amish enclaves for sale on the larger cultural and economic markets. Along with their wares, Amish women offer up their image, their competence, their sedimented craft-knowledge as actual and perceived guarantees of pastoral quality to non-Amish consumers. Quilts, clothing, bags, garden produce, jarred and canned preserves, baked goods, cheeses, simple toys, and other products from the woman’s

⁶⁷ The subtext here—economic stability that has been much needed in a time when agribusiness has taken over North American farming. The boom in agribusiness along with rising land taxes/costs has pushed many Amish farmers into full-time craft work.

⁶⁸ Two aspects of craft practice that stay important to the Amish: aspects of scale and aspects of utilitarian versus consumptive production. The first of these is important as families and church districts in Lancaster maintain their separation from the larger cultural environment. Issues of scale speak directly to matters of tradition and technology. Lancaster church districts see small-scale, family enterprise as a way to maintain the integration of work and family life, a way to preserve social equity, a way to avoid cultivation conceit or individual pride, and a way to prevent baptized adults from backsliding due to increased outside contact or influences (Kraybill and Nolt 2004). Subsequently, the shift between utilitarian productions intended for in-group use (as the definition of craft above entails) toward production for the consumer is not unlike the story of shifting craft production in any number of “traditional” communities throughout North America. See (Whisnant 1983) for a good discussion of this phenomenon in Appalachia during the 20th century. As a large market for Amish-made goods continues to grow, the communities have been required to open up a cultural dialogue with outside consumers about processes, design, and marketing.

realm⁶⁹ once *for* the Amish family are now *of* the Amish family. That prepositional shift helps expose these objects as actants. Indeed, all of these women's items are materials that participate in the course of action (Latour 2005). They carry and exert the power of economic stability for struggling families, the practices infused over generations, the ability of survival for widowed or unmarried women, the stereotypes of a simple and unquestioned lifestyle, the chimera of traditional authenticity, and the outsider assumptions of quality and wholesomeness.

There are four fields I would like to discuss where craft plays out in Amish communities of practice. The first arrives directly below in an elaboration of a few artifacts that work hard as busy actants in the cultural world of the Amish: the female Plain dress and the *kapp*, or head covering. As suggested above, these are explicitly gendered items and chosen here both as a result of my own ability to interact with them and as a point of visible reference to the Amish by most outsiders. Another field where craft becomes a relevant concept is caring for the body, particularly the tactile, un-authored handicraft of working with the body. This will be covered in the next chapter as one of the primary factors in the decision matrix for Amish negotiation of their plural medical system. The third field of craft comes in at the Clinic for Special Children in dual ways: the clinic itself as a site for craft production of medicine and the community's economic support of CSC via yearly quilt auctions that literally trade on their community's cache as craftsman in order to raise the money for treating their children's illnesses. Last, the Amish body itself can be understood as a site where this crafting is extended into the embodiment of Amish collective identity. These last two fields will be taken up in chapters five and six, respectively.

⁶⁹ There are, of course, "men's items" involved in microenterprise, in homemaking, and in Amish craft-practice in general. Some examples: furniture, lawn adornments, birdhouses, carriages, trailers, horse tack, small machinery inventions, other woodworking products. Amish craft practices and material culture have retained this gendered split; even in families where a female business owner is the primary breadwinner, the types of work considered acceptable for men and women remain strictly delineated (Kraybill and Nolt 2004).

As seen in the case of transportation, technological choices are also material ones tied up in an Amish sense of the literal and figurative spaces they inhabit. The technologies they choose to take up or reject shape the cultural artifacts available in their communities of practice—and vice versa as material choices can be seen as the result of and the powerful mediators of Amish mutual separation. Team travel, plain dress, community schoolhouses, even the Amish taxi cab participate directly in the dual horizons of binding the community together while separating it from worldliness. It is opportune here to highlight a few more elements in Amish materiality as further introduction into the lives of Amish in the Lancaster area. Some of the features I get asked about most frequently, other than the car, are plain dresses, head coverings, and energy use in the home. Let me cover each of these in turn.

Cultural artifacts: Plain dresses

Mid-morning, after the younger kids were off to school, Sadie Graber and her oldest daughter went into Zook's Fabric on Old Philadelphia Pike in Intercourse, PA. Although practically adjacent to a prime Amish tourism trap, the Kitchen Kettle Village, Zook's and many of the other small businesses in the heart of Intercourse are frequented by Amish patrons. This is the center of one of the most densely populated Amish areas in the world. Mingled between the RVs and tour buses streaming in and out of the Kitchen Kettle and numerous other attractions all around the area, Amish families go about their business in buggies. Kitchen Kettle boasts a high-end quilt shop; it draws in tourists ready to spend top dollar on Amish-made (and other) textiles in a bright and spacious space meandering through a beautifully remodeled historic house. Zook's, just a hundred yards away, sits in a boxy addition to an older brick home with a large sign above the door listing their phone number and the phrase "Zook Fabrics: Quality Fabrics for

Quilting and Sewing.” If there is a locally made Amish quilt over in the tourist shop, this is quite likely the place where the fabric came from. The inside of the store is neat and clean but full to the brim with fabrics. Connected at the back is another shop, Nancy’s Notions, containing any possible notion a seamstress or quilter may need.

Rows of colorful bolts swell into the aisles as Sadie and Levina head straight for the dress material over on the west side of the shop near the roadside. Some Lancaster districts prefer a more limited range of colors although some women may feel more freedom to broaden the spectrum. But any Amish frock will be a solid color⁷⁰. These are all polyesters, the standard for Lancaster Amish clothing. Even coats and formal men’s suits are usually made from polyester instead of wool. “Polyester wears better,” Sadie mentions, “and cotton just requires too much ironing. Better working for us, that is polyester.” With one hand she pulls out a bolt of medium blue fabric with an almost imperceptible little pinstripe running through the threads and immediately whips toward the blacks and grabs a bolt there for aproning. We move through the store, Levina with a bright lavender bolt under her arm that, like her mother’s, appears solid from a few feet off but has a sweet textured check in the fabric when inspected up close. After getting a few yards of each cut—about four to get an adult dress and another for the six-year-old, plus one and a half yards for aprons—they grab rimmed, center-less snaps and thread that match the fabric colors almost to a tee. Sadie runs into another friend, Elsie Hochstetler, picking up some premade ties for making coverings. Nancy’s Notions carries other premade items for the Amish

⁷⁰ Everyday clothes will indeed range the spectrum in the central Lancaster area but certain colors come in and out of fashion. More conservative Amish in Pennsylvania (and certainly elsewhere) will typically stick to a darker spectrum of blues, maroon, or purple. If lighter pinks or lavenders are worn, they are usually muted shades. White is worn when a woman is married and buried; black dresses are used for some church services, funerals, and during prescribed periods of mourning-dress.

wardrobe as well—a handful of aprons, jackets, bonnets with stand-up crowns⁷¹, straw hats, locally made steel hairpins, dark hosiery, and other things that would not need to be altered exactly to size.

Back at Sadie’s house she opens a file cabinet and pulls out folders labeled with the family members names. Inside are yellowed envelopes with patterns, many cut from newsprint. Meanwhile, Levina unfolds a large piece of cloth out onto the living room floor and begins cutting her own pattern out with scissors while Sadie uses a large sewing table with a mat and rotary cutter. They bounce around the rooms mindlessly with the effortless movement of having done something a million times. Levina has been making dresses since she was young, starting with doll clothes, and now that she is sixteen and out of school she makes her own as well as some for her younger sisters. Pieces are being carefully pinned together at expert speeds and soon they are off to the sewing machine—a sturdy pneumatic model recessed into Sadie’s wide sewing table. There are windows on three sides looking out on a pristine autumn day and the view from the machine is as idyllic as could be imagined. A couple of cows graze in a field and rows of harvested corn terminate at the long lane lined by a row of red scooters discarded for the day as the kids are off at school.

Despite appearances, Amish dresses have faint differences in cut and style that go in and out of fashion in the district. There is no rote pattern that is enforced or formally distributed to require all dresses, suits, or sewn clothing to look exactly the same. The plain dress and apron are not a standardized uniform as much as they are a vernacular expression of a laminated collective identity. But even in a lamination, discrete parts of the flattened whole peek through. Color

⁷¹ Girls and women use these thick, black bonnets with a delightful wavy crown across the top in the winter—usually over the regular covering—as a kind of “snow bonnet” or protection from the extreme cold. Made of a thick felt, they offer great insulation and cover the back of the neck with a flap.

choice and these small differences in dress patterns allow Amish women to take part in their own, if minuscule, fashion trends. This may arise in slight changes of cut, adjustments to the pleating, or a subtle decorative stitch. Most notable are the variation on the sleeve detail of a dress. A small opening for individual flair, sleeves are finished differently⁷²: a v-shaped notch, an overlapping cuff, a horizontal rib, a ruched center, a scalloped stitch, a little box pleat. Sadie notes as she is cutting the fabric for her sleeve cuff, “Go upstairs and look in Barbie or Levina’s closets—the young ones are full of colors and different sleeves. But once a bit older, I tend to stick to a few colors and my standard sleeve—I use a notch, flat and looks clean.”

Despite some of these quiet differences, the dresses across an individual closet, district, and even settlement are mostly similar. In Lancaster, women’s dresses are to mid-calf or below with pleating at the waist and shoulders. Often, a single pleat runs down the back of the bodice, echoing the back of a cape cover, even when not in use. Similarly, the pleating at the shoulders up against the flat arm openings echoes the cape. Dresses are fastened with snaps or straight pins up the front of the bodice—never buttons or zippers. Although always obscured by an apron, many women include a pocket on the front of their skirt. Black aprons are always worn except for white church versions and are attached by straight pins or waist ties depending on the type (half, full, bib, “good” meaning formal, with cape) designated by the work or occasion. The skirt is gathered with symmetrical pleats in the back and in the back center of the dress a small, semi-circular flap of fabric is sewn in between the skirt and bodice creating a tab or *leppli*. Scott suggests that this tab is a shrunken vestige of the peplum from the 18th and early 19th centuries; this widespread style indicated a skirt with an unattached, jacket-style top that buttoned up the front of the bodice and overlapped the skirt with a wide peplum across the back and sides

⁷² Note that this is all in the finishing—not as an embellishment. All of these changes are made in the way the sleeve cuff is cut and sewn. There are not pieces added or adorned onto the fabric.

(1986:90-91). Indeed, the Amish front-snap bodice, although now attached, echoes this idea and a more conservative district in the far south or further out in Pennsylvania may incorporate more of a back-centered mini-peplum in the place of the *leppli*. Sadie gave a different reason for the small *leppli*, noting “the bible says we should attach something to our clothing to remember God all through the day. We should have something fastened onto clothes.”⁷³ After the pinned fabric had been run through the machine and transformed into neat, tailored dresses, Levina presses all of the new clothing with a cast iron that was heated on a single burner gas plate. The iron has a detachable handle so it can be deposited on the flame to heat and picked up with the cool handle for use. Levina uses a spray bottle of water to create steam and places a thick ironing cloth between the heated iron and the fabric to prevent scalding. With three new dresses completed, pressed, and hanging from the molding on the sewing room door, the women sit down at their large kitchen table for a lunch of turkey wraps, soup, chips, and whoopee pies brought in from a freezer.

Cultural artifacts: the *Kapp*

A few weeks after running into Elsie Hochstetler at Nancy’s Notions, I visit her home just north of Bird In Hand. Elsie’s husband works in a shop that makes children’s play structures and other outdoor furniture. Her children are all school-aged, and she has a busy household to care for. Additionally, her sewing is accomplished enough that she often makes suits and takes

⁷³ Amish prohibitions and techno-material standards based on biblical passages are almost solely taken from the New Testament (although the Old Testament is known and read, the Lancaster lectionary includes only New Testament passages, primarily from the Gospels). Sadie’s, however, seems to be a reference to the old testament Mosaic law of wearing fringe on the clothing—interpreted in Judaism as the basis for *tzitzit*. For example:

The Lord said to Moses: Speak to the Israelites, and tell them to make fringes on the corners of their garments throughout their generations and to put a blue cord on the fringe at each corner. You have the fringe so that, when you see it, you will remember all the commandments of the Lord and do them, and not follow the lust of your own heart and your own eyes. So you shall remember and do all my commandments, and you shall be holy to your God. (Numbers 15:37-40 NSRV)

other orders from Amish inside of her district⁷⁴. On the counter aside her wide sewing table sits a tidy row of delicate-looking white coverings in various states of construction. These are known as a *kapp* or sometimes referred to by others as a prayer covering. In the Anabaptist world the term covering is used both as a noun and verb—always referring to the practice of a woman’s placing some sort of cloth dressing over her hair and referring to the cloth itself. There are a wide range of covering styles traditional to different sects, churches, and settlements⁷⁵.

In Lancaster, there are two standard layers of head covering for an Amish woman: the hair itself and the *kapp*. First, a girl’s hair is never cut from the day she is born; once it is long enough, the Lancaster Amish use a center part, twist or “roll” the sides down from the temple to the nape of the neck, and twist or braid the rest into a bun fastened by u-shaped steel hairpins. Young girls don’t usually wear an additional covering or prayer cap except perhaps in church, but they certainly wear fringed scarves tied around their head and chin when it is cool or thick bonnets in cold weather⁷⁶. Girls will typically pick up the practice of wearing a *kapp* in adolescence; they are marked moving from girlhood to womanhood, well before they make the decision to be baptized into the church. Refraining from cutting a girl’s hair and covering the head with a *kapp* are practices that root directly in biblical teachings. The Pauline directives concerning head covering are blunt and tied up in gender expectations for the community⁷⁷:

⁷⁴ This kind of intra-*Gmay* trade specialization is common. It seems obvious that an Amish family that makes furniture would go up the road to the dairy farmer for milk. But the same ways of playing to one another’s strengths and resources applies to all kinds of hobbies and trades. Some Amish women are simply not great at (or don’t enjoy) baking while others may not have great sewing skills, so families trade and sell among themselves frequently.

⁷⁵ See (Scott 1986:99-103, 120-140) for an overview of covering / cap styles across Plain dressing populations.

⁷⁶ When an adolescent or older woman who wears a *kapp* also dons a bonnet or scarf, she does not remove the *kapp*—the other elements are simply placed overtop her white covering.

⁷⁷ Note that the Amish do not differentiate between current social practice and the sociocultural contexts of the Pauline directives to the arguably disreputable Corinthians as a more liberal biblical interpretation tends to do. As textual literalists, the Amish take Paul’s instructions on face value as the word of God for all people in all times. In reference to head covering, Scott (1986) makes this point as well.

But I want you to understand that Christ is the head of every man, and the husband is the head of his wife, and God is the head of Christ. Any man who prays or prophesies with something on his head disgraces his head, but any woman who prays or prophesies with her head unveiled disgraces her head, it is one and the same thing as having her head shaved. For if a woman will not veil herself, then she should cut off her hair; but if it is disgraceful for a woman to have her hair cut off or to be shaved, she should wear a veil. For a man ought not to have his head veiled, since he is the image and reflection of God; but woman is the reflection of man. Indeed, man was not made from woman, but woman from man. Neither was man created for the sake of woman, but woman for the sake of man. For this reason a woman ought to have a symbol of authority on her head, because of the angels. Nevertheless, in the Lord woman is not independent of man or man independent of woman. For just as woman came from man, so man comes through woman; but all things come from God. Judge for yourselves: is it proper for a woman to pray to God with her head unveiled? Does not nature itself teach you that if a man wears long hair, it is degrading to him, but if a woman has long hair, it is her glory? For her hair is given to her for a covering. But if anyone is disposed to be contentious—we have no such custom, nor do the churches of God. (1 Corinthians 11:3-16 NRSV)

Covering is a common practice across many Anabaptist sects and only in the last few decades have the reformed and liberal branches of the Mennonite church let go of covering as a standard expectation. But conservative churches, Amish, and other Plain Anabaptists “put head covering on an equal basis with the doctrines of communion and baptism” (Scott 100:1986).

A great deal may be coded in the language of the covering; it can tell the observer what kind of church the woman attends, what geographical area she comes from, how conservative or liberal her congregation is, and sometimes additional information about marital status or other social markers. Color, material, types of ties, if the ties are actually tied or worn loose, ear covering, pleats, smocks, seams, and opacity are all aspects of the *kapp* that are not only dictated by the community, but can indicate various things about the wearer to other Amish both within a settlement and outside. Reading the *kapp* as a living text can indicate membership and geography. For example, the highly recognizable head covering in Lancaster districts will be heart-shaped, include a single pleat, and a back drawstring, while one group of conservative Swartzentruber Amish in Ohio will wear a thick broadcloth circular covering with multiple pleats and a back

bow. Reading the *kapp* as a living text can also indicate social and bodily status as a female within a particular church district. For example, in many Amish districts across North America, young, single women of marrying age or nearing marrying age will wear a black version of their local *kapp* in church to set them apart from the married women. And because baptism and marriage often coincide, this not only marks them as virginal, available prospects, it may also mark them in the liminal coming-of-age state associated with *rumspringa*.⁷⁸

The coverings on Elsie's worktable are standard for the Lancaster area and seen all across the settlement. They are made of a soft white organdy. The ties are made from the same material with a gentle edging of white thread.⁷⁹ Exclusive to Lancaster, these coverings sport the distinctive heart shape from the back, divided by a single pleat down the middle. The brim is relatively narrow and usually sits behind the ear. Elsie's current projects will all go to friends in her own district and the samples on her shelf seem to sport the same width ties. The wider the tie, the more conservative the individual advertises herself to be. Ties are narrower in the most progressive districts. But this can also distribute by age; older women tend toward a wider tie. Elsie's designs also sport a small, almost hidden drawstring gathering the material at the back of the covering in order to allow for different amounts of hair secured under the *kapp*. Women secure them forward from the crown of their heads by a straight pin into the hair. A delicate beauty folds between the carefully stitched pleating across the crown of the covering. Later on, chatting all the while, Elsie deftly creates the folds with her fingers along a piece of cut cloth and forgoes any measurements to spread them symmetrically along the crown. "I enjoy making these ... sometimes we tend to just put it on in the morning and forget, it's just part of the day. They

⁷⁸ *Rumspringa*, or "running around," is discussed further in Chapter 6

⁷⁹ Sometimes ties are made from white satin ribbon.

get tattered, old. Little holes from the pins up here. But I enjoy them because here [on the head] we face God. It's a gift to stitch the *kapp* that goes to God.”

The Amish woman covers her head, almost at all times, by demand of the *ordnung*, the word of God, the husband, the community at large, and the self. Even the unbaptized are never shorn and shepherded into covering just as their bodies begin to mature—applying the social habitus, female children are braided and capped despite their status as non-members. Thus, the habitus of covering is familiarized; moreover, the covering itself produces parts of these durable dispositions. These are the interactive practices through which habitus is gained; these show a process of familiarity, rather than explicit learning, in physical domains (Bourdieu 1977, 77-87). Indeed, the Amish in practice pay special attention to the mediating power of artifacts. But how does play out in Amish mutual separation? Consider the covering first as mediator in the interaction between these communities and larger groups with which they interact. Would this reveal Amish collective identity as something wholly different from surrounding English conceptualizations of the autonomous individual as a natural link between an objective body and subjective spirit? Can we access this potential realm of difference via the social power of cultural artifacts?

The covering explicitly engages self and body as it is acted out in social arenas. Bourdieu's habitus describes how dispositions react to perception and action and incorporate the objective social realms into the subjective experience of the self. As he concentrates on individual consciousness as “socialized subjectivity” resulting from internalizing social forces (Bourdieu and Wacquant 1992), investigating the covering begs us to shift from the particularity of bodily practice and the process of subject formation to refocus back out on the *social* habitus by theorizing how the Amish sense of individual bodily experience may be affected by the

collectively constructed identity of a social body and vice versa. Selfhood, again, can be cast as an assemblage from cultural resources that is itself a form of practice (Friedman 1992, Holland, et al. 1998). Within this assemblage, I venture to turn over the subject nature of an Amish social habitus and the object nature of the covering. The covering itself becomes the actor as it engages the intimate body and influences bodily experience: the unshorn hair, the weekly washings, the constant middle part pulling tight on the skin, portions twisting into braids, hair pins, straight pins, essential oils on the scalp, the coding in the *kapp* construction. To begin engaging this exchange, let me restate and expand some of the above description.

Characterized by a construction common to the Lancaster settlement, the coverings on Elsie's worktable distribute themselves all across the settlement. The soft white organdy of each *kapp* puffs out gently from the shelf with identically thin ties dangling along fine edging of white thread. Each stands proud with dual puffs separated by a single pleat creating a distinctive heart-shape and marking them as exclusive Lancaster coverings. These *kapps* will distribute among Elsie's closer contacts in the district, and each will settle behind lavender-scented ears while trying to grab the heavily parted hair at the center by a straight pin passed again and again through the pressed weave of its narrow brim. The *kapps* of older women have a harder time with this, as the constant onerous center-part over decades of combing and pulling causes the hairline to begin receding out from the middle. But each folds and pleats in over itself on a delicately curving crest to become the graceful shroud shown proudly in the presence of God.

The desire/tendency to dualistically divide subject and object creates the paradox itself, upset (by making an apparent confusion) because of the difficulty of placing the object-thing on one side or another of the dichotomy. The Amish become the object in direct reception of this engagement with the practices around *kapp*. The subject/object dualism here is not simply made

non-dualistic by virtue of a permeable boundary nor is it erased to form some sort of globular monism, but it is inverted completely in moments of synchronic dynamism. In those moments, we can glimpse the subject nature of the *kapp*, particularly as it becomes an unconscious agent acting upon the woman. Elsie said, "... sometimes we tend to just put it on the morning and forget, it's just part of the day ...". This "affinity to the unconscious" begets what Miller calls the artifact's "extreme visibility and its extreme invisibility;" it accounts for how much material culture can be overlooked as a factor in social dynamics (1987:108). The covering's affinity with out-of-awareness also allows it to play an important role in marking and making different forms of social reality. With particular objects, subjects are exchanged and dualism collapses into the synchronic dynamism mentioned above; the subject is not "constituted through its opposition to and encompassment of the object; rather, it is amplified by merging with the object" (Keane 2005:200).

Cultural artifacts: electricity and home life

Amish interactions with electricity and energy use also provide a good space to consider these porous divisions of subject and object. Similar to decisions around transportation, using electricity is not prohibited by virtue of its being sinful or morally inappropriate. Using electricity, in fact, is not prohibited at all. Most Amish utilize some form or another of electricity; more conservative or traditional groups use less or none while more reformist groups incorporate various allowances in the *ordnung* for electricity in the home and workplace. In Lancaster, most Amish use multiple forms of electricity on a daily basis with most of it originating from natural gas or diesel engines. Electricity prohibition bans tapping into the public grid. "Those lines tie you away from our people," Paul Lehman points out. "We'd like things

better to be tied up with Amish ways instead of tied up with buttons that can't be figured.”

Staying off the grid serves Amish mutual separation in two ways. First, it maintains a physical separation from larger powers, real or perceived⁸⁰, like the state or corporations. Being “tied away” by powerlines indicates reliance on outside forces in direct opposition to the Anabaptist historiography as a social movement in direct protest of state control. Second, it has a direct impact on both the objects and streams of outside information brought into the home. Once you've tied yourself to outside forces, those forces pour into the home and into cultural practice as extensions of the outside literally flowing through the walls and streaming into the living rooms via electrical outlets. Televisions, radios, and computers bring a multitude of informational disruptions to worldly separation all while discouraging the durable cohesion of the collective identity formed when people spend daily time talking to one another. Microwaves and dishwashers bring noisy chaos as they pull women and children away from daily work that binds families together. Being “tied up with buttons that can't be figured” pulls the subject out, it picks at the individual laminated in the collective, it tugs practice away from traditional nodes of knowledge, it disrupts the unconscious sedimentation of durable dispositions. Outsiders often other the Amish by their opposition to electrical objects, but this opposition does not constitute Amish as subjects from their emic perspective. Seeing how practices around energy consumption merge Amish personhood with cultural artifacts can collapse the dualism. The section to follow pulls on this thread of energy use and how it weaves the Amish object and subject together in practice.

Driving up to Ruth and Paul Lehman's home is similar to driving onto many Amish

⁸⁰ Given gas controls and subsidies, an argument can certainly be made to counter that the use of natural gas and diesel places the Amish in direct use of the state system. Most Amish I've talked to about gas use perceive their gas as coming from the small distributors, often locally operated, that sell to their farms. It's unclear if the Amish are simply unaware of the connection between petroleum prices and the government or simply unbothered by the apparent contradiction between using gas but refraining from the grid on the basis of separation from overarching political powers.

farms in the area. It's a bit confusing where to park, what door to knock on, even which house exactly you are supposed to be calling on. A stack of mailboxes at the road indicates this as roughly the right address, but there are no numbers on the houses, so it's anybody's guess. The Lehman's lane curves back with a farm on each side and three houses to choose from. First, to the left is a small farmhouse and large white barn separated from the lane by a newer carriage house and small grazing area. To the right is a larger farmhouse and up further, a very new house sitting where the lane turns to terminate behind a massive blue barn built into the side of a sloping hill. As it turns out, Paul Lehman's nephew and family inhabit the older house, barn, and carriage house on the left. They have seven kids and run a market stand selling pies and other baked goods. Paul's son-in-law, Michael, who lives at the end of the lane with Maggie and their two young children, farms the property on both sides of the lane.

Maggie and Michael's house is less than ten years old and typical of newly built Amish houses—a mix of neo-colonial and farm house aesthetics with multiple entrances including wide covered porches across the front or sides, dormer windows, and an exterior mix of stone veneer and dark-shaded siding. Their house boasts two full residences—the 5 bedroom, 4 bathroom section that they live in and a smaller 2 bedroom, 2 bathroom section likely built as a *grossdawdyhaus*.⁸¹ The basement level is all one open room with its own extra kitchen fixtures along one wall; a basement purpose-built for holding church when it is the family's turn and more convenient climate control compared to holding it in the upper level of the blue barn as they used to. Paul and Ruth are definitely not ready for a *dawdyhaus* and still live in the old farmhouse to the right on the lane where they take care of Paul's nonagenarian parents. Like

⁸¹ Often included in newer construction but usually built on to older houses as an addition, the *grossdawdyhaus* or *dawdyhaus*, is a small but usually self-sufficient dwelling for the “grandparents” to retire into once they are unable or uninterested in maintaining a full household or farm.

many older Amish homesteads in Lancaster county, it's easy to carve out the original structure at the center—an historic brick farmhouse in the PA German Traditional style with a steeply pitched gable roof, dual gable end chimneys, and a four over four façade.⁸² But around that hearty middle are add-ons and remodels tumbling in succession from the back and sides of the swelling structure. Paul's parents once inhabited the main area encompassed by the oldest part of the conglomeration but now live in a section of the house built on in the 1950s. Joy and Paul (senior) round out the Lehman property as a four-generation Amish homestead.

Expectedly, there are no overhead lines running to the Lehman houses. Around the back corner of Michael and Maggie's carriage house, solar panels face south and west over wide fields sloping across the horizon to the next farm. These panels power the electric fences to keep the animals in and one section is wired to an inverter housed in the basement and used for charging household batteries⁸³. Just as the English commonly have a garage or carport adjacent to their home, most Amish homes in the Lancaster area have a carriage house in a similar position. Coming past the carriage house and through the door in many Lancaster area homes feels similar to entering any house—somewhat spartan, but familiar nonetheless. Many homes, Maggie and Ruth's included, are arranged around a main central open area with the kitchen at one end, a large table that can seat the whole family, and a living room or seating area opposite the kitchen. Things are made strange for visitors in unflinching habits of living with a wired house. Opening the refrigerator, it's oddly hard to find things in the dark—there is no internal light bulb because the refrigerator is powered by propane. The ceilings are strangely smooth, white expanses

⁸² See (Pennsylvania Historical & Museum Commission 2013) for a full description of this style.

⁸³ These are common uses for solar panels and the typical extent of their use. Lots of Amish, even in Lancaster, have no solar additions but the energy source is used within acceptable boundaries in many districts. The most extensive use of solar I've ever seen was in a brand new house that was wired with standard electrical outlets on a few walls that drew power from solar panels on the roof. The family that built that house still choose not to install light fixtures or other most ostentatious use of electrical energy, but the luxury of having one outlet in most rooms meant this ethnographer had somewhere to charge her laptop!

unbroken by lighting fixtures or ceiling fans (save the occasional skylight or suntube in some homes). Having excused oneself to the restroom, reaching to flick the switch results in no partner to receive this electrical advance. And unless you know how to expertly light a wall-mounted gas fixture with its little white mantle dangling in the air, you'll likely be peeing in the dark. Other common sights include tall lamps connected to a wooden cabinet on wheels. The cabinet houses a small propane tank, like the type used for an outdoor grill, and the lamp can be rolled from the kitchen or eating area, into the sitting area at night for evening reading and talking. Many Lancaster Amish also use some battery-powered portable lights in the evening and particularly appreciate the low-energy requirements of new LED bulbs.⁸⁴ Batteries for lights and other small electronics⁸⁵ are charged using generators (or the infrequent solar system, as mentioned earlier) hooked to a power inverter.

Up at Maggie and Michael's, the floor in the main room includes a large floor grate where heat from a furnace in the basement below is able to rise right into the main living area of the home. That climbing heat is helpful on this blustery day. It's not windy enough, however, to keep Michael from the scheduled spraying of the fields with manure sludge, so Maggie has to get the clothes in off the line. Laundry is washed in a ringer washing machine powered by a diesel generator and then hung to dry⁸⁶. The water often gets recycled for multiple loads. Just as Maggie steps out onto the porch to reel the laundry on the long pulley-cable extending out over the backyard, Ruth and an Amish neighbor from across the street come quickly up the lane with

⁸⁴ On a recent trip staying with Amish friends in Lancaster I was delighted to be provided with an old brass candlestick base that had been retrofitted with a tiny LED light powered by a battery inside the (former) candle well.

⁸⁵ Other battery-powered electronics would be few and limited to functional items for the household. Some common uses for batteries, other than reading lights, include operating clocks, running limited equipment in the business setting (such as a fax machine or photocopier), and powering lights and flashers on buggies. Note that more conservative Amish groups elsewhere would likely not use so much battery power or any at all. For example, some Schwartzentruber Amish (the most traditional and conservative sects) still use kerosene lanterns on their buggies and may refuse all reflective lighting or tape.

⁸⁶ Some Lancaster households employ a spinner to begin drying the clothes and reduce the line time.

Maggie's four-year-old, Rachel, trotting on behind them carrying two kittens high in the air by the scruffs of their necks. The women gather in Maggie's kitchen and in one graceful swoop across the room she deposits the laundry basket by the window, warns Rachel to get those cats back to the barn, pops the flame up on the gas stove to boil water, retrieves a tin of cookies from the counter, and spreads cups across the kitchen table. The older women are already sitting on benches along the side of the table, rattling on about the Moyers' upcoming wedding, when Joy comes through the door and hobbles to a seat at the table. Through the side window, the scene becomes clear. What looks like a huge addition to the back of a neighboring farmhouse, stands out on the picturesque autumn scene like a sore thumb. An enormous plywood room almost dwarfs the first level of the home and the faint banging of hammers can be heard from the little ant-hill of straw-hatted men swarming over the structure. It clearly looks like a remodel; perhaps they are adding a larger living area or putting some new bedrooms with a bathroom on the back? It quickly becomes clear that this is the Moyers' place across the field and what looks to be an obviously permanent addition is in fact quite temporary. The closed-in structure across the back of the house will serve as the large area needed to host a wedding; it will be expertly erected and then carefully disassembled the weekend after next⁸⁷.

November is wedding season and the standard day for couples to take the vow of marriage is Thursday.⁸⁸ It's a serious but exciting time; young people must be already baptized

⁸⁷ Wedding services are very similar to a standard church service, clocking in at just about three hours long, the couple takes the vows of marriage just in the few minutes at the end of worship. Kraybill, et al. explain the services in brief (2010:115-117). The set-up for the ceremony requires a similar set-up to as church, so the bride's family needs a large and flexible space to put the worship service and the corresponding meals feeding upwards of 250 people. Some families build these temporary additions on or near their home while others may use an Amish-owned shop warehouse or similar large space. Even families with a church-worthy basement or barn must often employ additional space-finding methods in order to welcome everyone the day before, host the service, serve lunch and dinner meals that are standard on wedding days, and see everyone off the next day.

⁸⁸ Due to the relatively few number of available dates from the end of October to the beginning of December, it's become common, if untraditional, to start holding some weddings in the early spring as well. Also, as Kraybill, et al. point out, now that industry has broadened in the community, some families will choose a Saturday wedding to allow for Amish who work M-F for English employers (2010:114).

into the church as full members and it is not uncommon for the baptism and marriage to happen in the same season.⁸⁹ In the spirit of Amish mutual separation, the wedding stands as a holy rite that remains the “spiritual property of the church, not the couple” (Kraybill et al. 2010:115). Instead of the celebration’s revolving around the couple as it does in English weddings, the festivity centers on the coming together of community—both in a figurative sense as two families are joined together and the church tradition continued with a promise of procreation, but also a literal sense as the *Gmay* spends days preparing, setting up, and later breaking down the wedding celebration. The labor gets multiplied by literal horsepower and combined efforts of many people. The full-day celebrations are always bookended by many of the wedding attendees arriving a day early to help set up and staying a day late to clean up the aftermath. Where the English may celebrate efficiency aided by power tools to quickly erect a structure or industrial kitchens to prepare several meals for a multitude of visitors, the Amish inputs flow from the community of believers joining to many hands to make light work.

As it turns out, ethnographers can be handy to have around because they are willing to drive people just about anywhere for free. On the Friday after the Moyers’ wedding, I spent much of the day shuttling people home to various outposts in Lancaster County. Visiting so many homes in one day gave me a window into the differences in relative wealth across the settlement. Generally regarded as some of the most wealthy and progressive Old Order Amish, the Lancaster Amish do see a spectrum of economic difference among districts. While there are always exceptions, those in the center of the county—like the Lehmans, the Moyers, and the Grabers—tend to be relatively well-off. Their farms and houses sit on some of the most fertile land in the nation and their cooperation with the tourist trade brings a great deal of income into

⁸⁹ Baptism is elaborated in Chapter 6

the community (Kraybill and Nolt 2004:154-155). As you travel east and south, the Amish become less affluent⁹⁰. (Don't go north, it's crawling with Mennonites!) Late that Friday afternoon, John and Lydia Kratz⁹¹ direct me along bendy rural roads out toward the Quarryville area. John gives directions from the back, interspersed with reverse interviewing of the ethnographer—questions fire one after another about who I am, what I am doing, where I came from. “North Carolina,” he notes, “that’s between here and Florida, yes?”⁹² Going to Florida, you pass through Carolina.” Lydia sits in the front with her quiet hands resting on her black apron. Her large, rough hands bear the sign of arduous labor. Pulling up to their farm feels reminiscent of a mountain holler with its ramshackle barn and weather-worn white farmhouse. A gaggle of chickens pecks at the dirt just in front of the porch and they barely shoo out of the way as we pass by. The Kratz house seems a bit darker than the sunny abodes up near Gordonville or Intercourse. The space still revolves around a large, central area, but heavy wooden beams interrupt the flow. Lydia crosses immediately, lighting two small kerosene lanterns and finishing the match by igniting a stack of kindling and paper waiting in the potbelly woodstove in the corner of their sitting area. The smell of kerosene drifts sharply through the air as Lydia opens a tall wooden pie safe with metal-punched decorative panels boasting a *dischdelfink* motif common to Pennsylvania Dutch *fraktur*. By far the most ornate thing in the room, the pie safe

⁹⁰ No quantitative study has been done to compare the asset levels or yearly income to the relative conservatism / traditionalism of a district's *ordnung*, but the observation often holds true that less wealthy Amish tend to hold onto more traditional technologies while more wealthy Amish may be more quick to experiment with new trends. Certainly, as you move into other areas of Pennsylvania, such as the Big Valley area, the local Amish live at significantly more modest economic levels than those in the heart of Lancaster. The Young Center for Anabaptist and Pietist Studies counts the districts in Lancaster County proper and a few in York County as officially part of the “Lancaster Settlement” for the purposes of population census.

⁹¹ The Kratzes have 4 young children who did not attend. This seems to be common for those traveling in for a wedding (as opposed to attending one in your own district); younger children tend to stay home but teens will often come along and congregate with members of their youth groups.

⁹² Not an uncommon geographical reference for the Amish in Lancaster and beyond. The village of Pinecraft in Sarasota, Florida boasts the most common vacation destination for Amish from multiple settlements. It is particularly popular for travel in the winter months when things often slow down for farms or businesses and “snowbird” Amish come to enjoy the southern sunshine for short or long-term visits.

contains art of another kind. Lydia shuttles an apple pie quickly out to the car as payment for the ride because I refuse to accept cash. The pie, already nestled on the floorboard, proves harder to refuse.

Conclusion

What began as a conscientious desire to maintain a voluntary religious sect held at arms length from the controlling forces of the state now continues in the thriving Amish settlement around Lancaster County. The term “at arms length” is intentional—the Amish are not anarchists or fully anti-government. However, their Anabaptist forbearers passed down a fervent belief that religion should be practiced as a wholly separate enterprise from structures of the state. The nation is indeed “under God,” and it would be blasphemous to pledge allegiance to man-made political hierarchies and secular authority. And because religion cascades into every detail of everyday Amish living, it becomes necessary to constantly weigh decisions about practice in light of how they impact the entire community and how they might help to enact the cultural world.

The joint horizons of Amish mutual separation—the binding of community via yielding individual selfhood and that community’s separation from the surrounding world—result in a collective identity that minimizes the autonomy of individuals while maximizing their difference from non-Amish. Mutual separation constantly emerges through practice. In that practice, the Amish pay special attention to the mediating power of artifacts, space, and time. Be it the team or the *kapp*, technological choices are also material ones and their results act as powerful mediators of Amish mutual separation. Personal behavior is unfailingly restricted from acting in a modern mode of unconstrained individualism. This restriction plays out through material and

technological choices that characterize the cultural artifacts of Amish communities of practice—transportation, dress, and energy use, just to name a few. In other words, Amish uses or refusals of technology are among the practices that help to “shield their subculture from the divisive pressures of modernity that threaten to tear their corporate life asunder” (Kraybill 1994b:33). This deliberate choice-making at the group level is described as the primary characteristic of their modernity (Olshan 1994:188).

These are not the only types of decisions that are tied up in an Amish sense of the literal and figurative spaces they inhabit. As evidenced above, Amish communities are sensitive to potential ramifications and consequences associated with various innovations and attach extensive logics to their decisions about technological incorporations. Technologies, as “other” to the group, are not necessarily seen as potentially hostile, but are simply constructed as logically incongruous with Amish life. A study of this dynamic, however, has not been applied to districts’ interactions with medical technologies, biomedicine, or genetics. The factors at play in these decisions sets the stage for understanding Amish negotiations of medical technologies. This section has touched on some of the larger nodes in the network of actants at play in Amish communities of practice. Later, more cultural artifacts will be uncovered in talk about health, medicine, money, genes, quilt sales, doctor’s offices. Change occurs with each new generation baptized and as each church-district dialogues with its own *odrnung*. This retention/rejection of technologies signals something more complex than a folk-group simply attempting to maintain status quo or reinvigorate traditional practices. It signals something more than objects as the material of culture. Uncovering these artifacts in practice enables us to see their active roles as actants pouring across the boundaries of the subject-object divide.

This chapter has emphasized the role of community in practice stemming from a unique

status as a historical post-social movement. To follow, I bring consideration of Amish mutual separation into realms of healthcare, embodiment, and genetics. The discussion here of community identity and yielded selves should not suggest that there exists no variation among individuals within Amish communities. Indeed, individuals' experiences with their individual bodies provide a space for continued investigation of personhood among the Amish and this becomes essential for understanding the wider social negotiations with medical models.

Despite the strict constraint of individual expression required by the *Ordnung*, most Amish youth choose to be baptized into the church. For example, this consistent growth has resulted in an 103% increase in total number of Amish districts between the years 1991-2010 (Kraybill et al. 2013:153). As we've seen, perennial negotiations with the appropriate incorporation of outside technologies have led this thriving minority toward a cycle of resistance to and negotiation with forms of non-Amish progress and modernity⁹³. Our next step here is to focus on these negotiations and traditions as they influence individual medical choice and health practices. Earlier, it was noted that collective identity minimizes the autonomy of individuals while maximizing their mutual separation. Now that the bounds and influence of the cultural world created in Amish communities of practice have been established, I'll forge ahead to illustrate how that cultural world manifests in health and medicine. Here, we can ask how do the Lancaster Amish approach health-care in general? Does a communally-dictated and spiritually-based understanding of the person influence submission to biomedical practices?

⁹³ This idea of cycling around "resistance and negotiation" is a common way of talking about the Amish and technology in the Amish studies literature—likely initiated with Kraybill's 1989 work *The Riddle of Amish Culture*.

Chapter 3: Medical Pluralism and Health Practices Among the Lancaster Amish

Introduction and Medical Pluralism

The goal of this chapter is to delineate the breadth of health practices among the Lancaster Amish. Together with the information from the last two chapters, this section will address *how key Amish cultural constructions show up in understandings of health and the body*. After introducing the concept of plural medical systems, I will discuss these constructions in relation to incidence of medical use, practitioner choices, and health economies.

Since the 1970s, medical pluralism and the “plurality of care-seeking strategies” have been perennial themes in medical anthropology (Castro and Farmer 2007). In the same period, Arthur Kleinman’s labeling of medical and health practices as cultural systems (1978:85) opened up these pluralities as uniquely suitable for anthropological study. While plural systems have often been conceived as a cosmopolitan versus indigenous dynamic (Leslie 1980), medical anthropologists have frequently investigated the introduction of biomedicine into indigenous systems and attended to the resulting hybrids and pluralities that arise as the medical knowledges and power structures collide. More recently, medical pluralism has come to encompass additional constructions of plurality including the more recent focus on implementations of medical and health technologies in practice. The study of health modalities, and biomedicine in particular, has to recognize a wide array of concerns including local “priorities about individual and community well-being” (Lock 2007:2). In choosing between medical settings and

technologies, members of a cultural group are faced with decisions, and sometimes dilemmas, as to what approach (or combination of approaches) may be most suitable, most socially acceptable, and most effective in addressing the body.

The Amish have not been suddenly introduced to biomedicine; the concern here is not how new technologies disrupt an indigenous health system. Instead, just as Amish settlements have engaged in other sorts of technological negotiations, use of various medical modalities have been gradually accepted or rejected with the slowed patience of *Gelassenheit*—that call to adherents to sacrifice self-interest, to give up personal motivations, to yield autonomy to the *Gmay*. Klienman notes that health decisions are typically made in what he calls the “popular arena”— the family, social network, and community contexts of sickness and care (1978:86). This description holds true, but only partially so for the Lancaster Amish. Decisions are certainly made in all of these arenas but normative health practices and the suitability of health technologies are intensely impacted by Amish collective identities emerging in the practice of mutual separation.

Unlike the prevailing medical context in which biomedicine dominates other medical practices, the Amish pluralistic system reflects mutual separation—their pluralism is a faith-driven, intentional removal from overriding, state-related hierarchies⁹⁴. Using non-state-favored medical technologies in Amish healthcare results less from a challenge to hegemonic forces and more from intentional separation from the non-Amish cultural currents affecting their community of practice in other arenas. To put it in terms an Amish person might use, they refrain from indulging in practices that encourage or reward the empires of man: secularism, scientific authority, higher education, and economic excess. Instead, they seek to honor the empire of God.

⁹⁴ This can be seen in compliment and contrast to Baer’s (2004) emphasis on ethnic and class minorities using pluralism to challenge the dominance of biomedicine and elite hegemony.

Seeking this goal, the *Gmay* must dictate acceptable relationships and acceptable boundaries that legitimize certain health practices and health practitioners.

Bourdieu characterizes the kinds of social relationships that exist among alternative sources of knowledge and practice such as characterizing health practitioners as competitive fields and as constituting sites of struggle for different forms of power. One thing at stake is the amassed and accrual of symbolic capital that is then used to reproduce the field itself. “Culture,” for Bourdieu, does focus on meaning, but that meaning is fashioned, replicated, and utilized by subjects operating within assemblages of objective fields in everyday life (2006:85). Such fields can be characterized by the struggle for symbolic capital. However, in the case of the Amish, a depiction of Amish medical pluralism as amenable to Bourdieu’s concept of a field of practice begs an important question: in a community that strives toward the rejection of *personal* power and prestige, does it make sense to imagine that symbolic capital is at stake?

The field of medical modalities that constitute Amish plural medicine emerges in the struggle to achieve *uffgevva*. This “giving up,” in the spirit of *Gelassenheit*, aims to create placidity in the community and avoid situations of social inequity; this results in the goal of similarity, the lamination of the individual as first and foremost a personification of the collective, even with regard to bodily dispositions. In other words, the sought-after capital is a state of denying capital any importance, a quiet parity where one is submerged in lamination of the collective whole. The symbolic capital gained by the community through faithful and consistent separation is a tool used by the Amish within their field of plural medicine to gain dominance in economies of the body and thus to reproduce themselves over time.

How, then, is plural medicine a field where Lancaster Amish collective identities are in practice? Fields offer people spaces of a sort within which they can navigate some part of reality.

Fields are spaces of “play and competition in which social agents and institutions which all possess the determinate quantity of specific capital ... confront one another in strategies aimed at preserving or transforming this balance of forces” (Bourdieu & Wacquant 1996:76). The field of education accommodates practices of learning, fields of the arts accommodate practices of aesthetics, and fields of medicine are one way to practice moral economies of the body. A first step in sketching plural medicine among early 21st century Amish settlements as a field of cultural practice is to identify the nature of bodily understanding. This certainly relates back to anthropological notions of habitus and embodiment, but more immediately relevant here are ways that bodies are understood as spiritual homes.

The given shape, condition, or characteristics of Amish bodies are a spiritual gift from God to the community that should be navigated for its advantages or challenges. Stasis of the body is determined not by man, but by God alone. It is considered an earthly task to care for the body as a vessel, but all Amish settlements have been strictly adverse to alteration, amendment, or embellishment of those vessels. Using the term vessel, however, should not imply that the body is understood as simply a container for spirit as it is in some Christian sects, that the two are fundamentally separate, or that the spirit is a priori the body. The two exist as the entanglement of flesh (from the world of man) and breath (from the world of God), and the Amish see them as inseparable—what one does to the body impacts spirit and vice versa. To this end, economies of the body are imbued with concerns of the spirit, and any experience with medicine and its practitioners will include the effort to keep these balances in check. This balancing dynamic sits at the heart of Amish economies of the body; the resources of physical and spiritual are both wrapped up in bodiliness and managed for the productivity of the community.

The plural medical system formed and being formed by a Lancaster Amish district responds to this dynamic relationship. Their theology as played out in physical practices dictates a balance of body with spirit, and they recognize this merging as a marker of mutual separation. The force of this cultural construction will become evident in some of the examples below. Amish districts respond to and incorporate medical modalities provided by others as part of a field of medicine to the degree that those pieces respond to and incorporate their expectations about the mind-body relationship⁹⁵. They accomplish this by employing an array of medical approaches specific to contexts of affliction.

Amish Pluralistic System

Simon Shenk looks out from his front porch on a cold January morning just as his English neighbor, Roscoe, trundles up his own driveway to get the paper. Simon, standing behind the team that had just been hitched by his oldest son, closes a heavy black coat of layered polyester against the cold, his greying beard flapping a bit in the morning wind. Roscoe shuffles around his blue F-150 in a red flannel bathrobe over sweatpants and fleece-lined moccasin slippers. Simon and Roscoe live just a few meters away from one another. One man with no grid-based electrical power, a daily commute by buggy to a small furniture shop two miles away, and a steadfast spiritual community holding up his family. The other with wireless devices scattered all over his house, a thirty-year career in the public sector, and two kids currently enrolled in state universities. But no matter the cultural worlds they inhabit, they both hold something considerable in common. Both of these men have human bodies. And both of these men have cancer.

⁹⁵ See Chapter 6 for more on embodiment, sacrifice, and the phenomenology of the Amish

It's not difficult to speculate on the illness career of Roscoe. His diagnosis came after not feeling well for weeks and struggling with fatigue. Managed by an oncologist at Hershey medical center, Roscoe takes up a familiar illness career—attempting to maintain control of his life, normalizing everyday activities, and operating in a relatively isolated bubble of not wanting to worry or bother the wider community with his family's needs (Muzzin, et al. 1994:1201). “We'll get this all figured out, we will,” Roscoe says. “Doctor Saunders up there at Hershey, he's going to set me right. The treatments are hard on [wife] Betsy, taking care of everything and all, but we manage. With the kids at school and the doctor bills, well, it's a lot, but the state [Pennsylvania] does right by us.”

Simon's illness career is less familiar. Beginning with his own bout of exhaustion and weight loss, Simon and his *Gmay* began a series of interventions along almost all strands of Amish pluralism—from chiropractors and chemo to boarding a bus headed for Mexico, he's seen it all. Simon's story will continue below, but for now Amish medical pluralism needs to be sketched out. In the Lancaster area, these plural approaches run along in five strands and each attends to certain sets of concerns. These five health modalities tend not to dominate or subordinate others (ie. a “traditional” or indigenous healing systems are sometimes found to be subordinated by biomedicine or the reverse) and certainly overlap in many instances. While it does seem to be true that they are used with varying frequency, each seems appropriate and applicable in its own class of bodily states. In other words, the interplay of these strands can be illustrated any number of ways: they can be made hierarchical by frequency of use, ranked by financial cost to the community, or listed in order of their potential conflicts with the spirit of

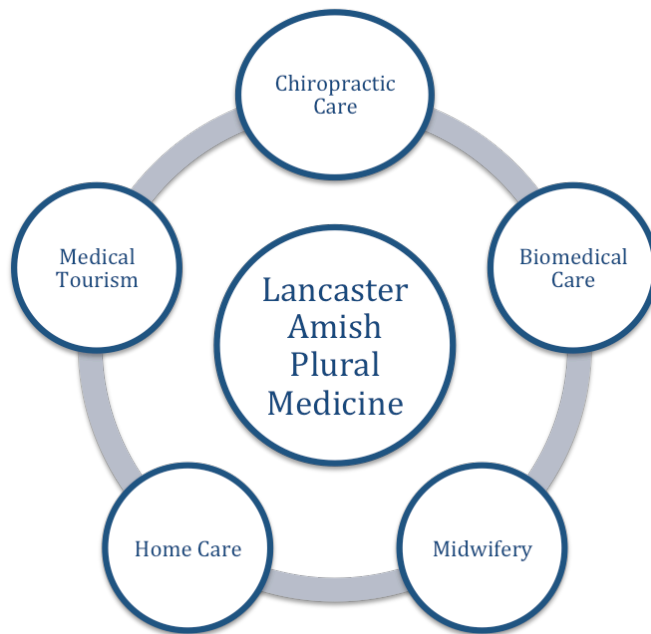


Figure 1: This model illustrates a non-hierarchical arrangement of approaches; note that the term "alternative care" is avoided here as not to relegate one type of care as normative.

Gelassenheit. But the predominant emphasis I found concerned their match to specific health needs. In the illustration above, they are simply diagramed as equal parts of a whole system. Continuing, each area in this field of practice will be outlined to further explain Amish health approaches and their uses as each gets specified to contexts of health and dis-ease.

Before I continue, however, the topic of powwowing or *brauche* should be briefly addressed. This category is noticeably missing in the construction above, largely due to the fact that *brauche* is no longer used as a specific category among the Old Order Amish in the Lancaster area. Powwowing, a folk-healing method originating in the Pennsylvania Dutch (non-Plain) communities is defined as “an unofficial traditional magico-religious practice—originating with and chiefly practiced by the Pennsylvania Dutch and emphasizing healing of

humans and animals, but with other goals as well—that uses words, charms, amulets, and physical manifestations to achieve its objectives” (Kriebel 2007:16)⁹⁶. *Brauche*, in the traditional sense, is no longer found among the Lancaster Amish for two reasons. Powwowing focuses on removal of hexes, protection via amulets, healing, casting out demons, finding lost items, and the like. In addition to magical objects (like the amulets), it relies on touch and incantation of spells—some of which come from established spell books and others lifted directly from the Bible. During the 20th century, many of these practices came to be seen as “devil’s work,” and Amish groups, particularly the more progressive, moved away from them. *Brauche* rendered the line between “black magic and white magic” too blurry (Kriebel 2007:204-207). The other reason that powwowing is not found outright, is that elements of *brauche* enjoyed by the Amish have simply been absorbed into the category I refer to as Home Care. Some may reject this analysis by claiming that *brauche* still exists as a secret practice among the Lancaster Amish. To the contrary, the use of some powwowing elements is certainly still around, but they have become too involved with other forms of Amish healthcare intervention to be well aligned with the Pennsylvania Dutch practice of powwowing. The few Amish naturopaths who might be known in the area as powwowers—*braucher* or *brauchfraa*—incorporate chiropractic approaches, reflexology, herbalism, and other home alongside traditional *brauche* uses of biblical incantations and laying on of hands.

Choice of Practitioner

The group’s enacted autonomy of *being* Amish puts them in positions to dictate which medical modalities can play in their pluralistic field as well as how these modalities (and the

⁹⁶ Kriebel’s book (2007) provides the most detailed and thorough examination of powwowing available. See also Miller (1981) where elements of the *braucher* (powwower) are conflated with chiropractic categories among the Amish.

actors associated with them) are incorporated. In the examples to follow and throughout the case study around the Clinic for Special Children, there are factors that weigh into the decision-making matrix for choosing a modality or type of practitioner. Some of these are similar to reasons consistently found to affect the choice of a certain model for addressing health or illness. But even those common elements have aspects intensified or deepened by Amish communities of practice. Cost of care is an essential feature in decision-making within this group that carries no medical assistance other than the aid provided by the church body as a whole. Amish families are acutely sensitive to continuity of care issues, particularly in light of most practitioners coming from outside of the realm of Amish practice. Appropriateness of care must fall in line with community rules of order, standards of Amish Aid, and the general spirit of *Gelassenheit*. Health practitioners' successful in retaining a practice among the Amish rely on intensive word-of-mouth referrals in a cultural world that not only places a great value on the experiences of others but where individuals interpret good outcomes for an individual as good outcomes for the whole, laminated social body. Medicine of any type will generally garner more favor among Amish if it can be conceived of as a craft practice with tactile work and material aesthetics. This is one of the more tacit formulations, and perhaps thereby one of the more interesting elements playing into a conception of Amish embodiment. Likewise, Amish consumers will always move toward practices with a higher perception of natural origins. The term "natural" here being the difficult one to define or interpret, even among the Amish, but its characterization often connects to the last category⁹⁷. Time and time again, what I call the foundational knowledge dualism

⁹⁷ While tempting to put the term natural in irony quotes throughout, I will refrain as I continue below. Just as in the English world, natural is both a buzzword, thrown about to sell products or services, as well as a real concern for some (but not all) Amish families. Likewise, the use of natural products may enjoy a double standard even within one household. One Amish mother spent an hour taking me through all of the amber-colored glass jars from her naturopath and explaining how she uses each one because they are so much more "natural and closer to God" than pharmaceutical "medicines from doctors and stores." Just after, she served kool-aid at lunch and made sandwiches using a sleeve of white bread from Costco containing additives such as

arises as a point of conflict in many decisions about the body—actions that reflect and exalt the knowledge of God are preferred to those that reflect and exalt the knowledge of man.

The likelihood of Amish peoples' choosing a particular strand of their plural system is shaped by the “kind of theories that the therapist will invoke: global, holistic, spiritual, rather than local, partial and physical” (Douglas 2002: 24). These “global, holistic, and spiritual” ideas are aligned with Amish concepts of “natural” and the knowledge of God. The “local, partial, and physical” are aligned with systems of the state, empirical science, and the knowledge of man. Consider the seven themes outlined here as the strands that weave through the pluralistic system, tugging at Amish decision-making and influencing the ways Amish bodies become actors in vast networks of health and wellness⁹⁸.

Paying attention to how actors talk about health decisions offers insight into the nature of cultural knowledge as it applies to illness, how this knowledge is applied by community members in evaluating illnesses, and the processes whereby treatment decisions are made (Garro 1998, Crandon 1986). A great deal of my analysis draws from these kinds of conversations and focuses on the themes and cases discerned from listening to people talk about health.

Complementary to this qualitative data, I implemented small quantitative study in conjunction with the Young Center for Anabaptist and Pietist Studies⁹⁹. Our sample (N=112) included Amish adults (44 males, 64 females). One of the more interesting measures asked respondents what kind

calcium propanoate and azodicarbonamide. She mixed the kool-aid, despite the red#40, with agave syrup instead of sugar because it “has no refining, more natural than the white sugar so your body will take it up better.”

⁹⁸ See appendix two for a redrawing from field notes that sketches out these areas visually.

⁹⁹ This study sample was not random and cannot be considered a representative of the entire Lancaster. Nor is it large enough for identification of factors affecting survey choices. However, it offers useful information as pilot data for designing a more widespread study in the future (with the hope of a corollary survey among English families from the same geography for comparison purposes).

of provider do they see most frequently for their healthcare needs and consider their primary provider.

Provider Type	% of respondents¹⁰⁰
Medical Doctor	37.61%
Chiropractor	38.53%
Nurse Practitioner	0.92%
Physician's Assistant	0.00%
Natural Healer	5.50%
Midwife	3.67%
None / Self	6.42%
Other	1.83%
Multi-Answer (checked >1 box)	5.50%

The response rate for medical doctor was actually higher than we had hypothesized. This could be a reflection of the fact that some of the limited sample was recruited via healthcare forums at Lancaster General Hospital. For example, when those respondents are removed from the sample, the number for medical doctor drops by six percentage points and that for chiropractor increases by two. These are just the kind of factors that could be explored more definitively in a larger survey of the Lancaster population.¹⁰¹ Even with these limitations, the data are interesting. The survey showed high use of chiropractic services and homecare categories when respondents were asked if they have ever visited these types of providers (even only once in their lifetime) or participated in this form of healthcare:

¹⁰⁰ Percentage determined using (n) as the number of respondents to the given question. (n)=109

¹⁰¹ A similar quantitative study with some similar results was performed in the Ohio-Appalachia area (Reiter et al. 2009). The Reiter study compared responses about usage of biomedical models with complementary and alternative (CAM) health behaviors. They collected data from Amish adults (62 males, 72 females) and English adults (64 males, 90 females). There is no discussion in their study of how their sample compares to the distribution of Amish in the area or how this sample might be representative of the Holmes County settlement as a whole.

Provider Type	Percentage Yes¹⁰²
Chiropractor	91.96%
Medical doctor	89.91%
Certified Nurse Midwife	51.52%
Lay or community midwife	27.87%
Herbalist	31.25%
Massage therapist	26.61%
Care Type	Percentage Yes
Supplements & Vitamins	82.88%
Personal prayer for health	59.18%
Herbal medicine	51.82%
Detox or cleanse	50.91%
Reflexology	41.44%
Homeopathy	38.74%
Meditation	16.04%
Medical Tourism to Mexico	8.11%
Acupuncture	3.77%
Yoga	3.74%

Chiropractic care

In the Lancaster area, chiropractic care is typically used to address minor injuries or as regular preventive medicine; it is employed for conditions with high morbidity and even in palliative care, but these cases are often in blended with other types of intervention. This modality is used in all age groups—from pediatric to geriatric care. Some Amish also use chiropractors for more advanced disease, post-trauma physical therapy, psychiatric care or mood adjustment, and to address infant and child behavioral issues. Chiropractic interventions in the Lancaster area can be divided into two large categories: chiropractors with formal training in the field who have been licensed by the Pennsylvania State Board of Chiropractic and chiropractors who have not been formally trained or licensed. The second of these sometimes advertises or refers to themselves as chiropractors or may use terms such as body manipulators, body workers,

¹⁰² These percentages are calculated in relations to (n)=the number of respondents to that given question. In all of these examples, the number of respondents to the given question was within 10 responses of the total number of those surveyed.

or cranial-sacral therapists. Virtually all of these practitioners are English; I never encountered an Amish body manipulator¹⁰³. A licensed chiropractor would argue that a cranial-sacral therapist is indeed *not* a chiropractor.

Most of the cranial-sacral therapists in the area have little formal training of any kind; many attend a weekend-long seminar or other short-form informational classes to become “certified.” One Chiropractor noted:

[Chiropractors do] true cranial-sacral work ... Wasn't a buzzword for me, it was just something I did ... I work both the cranium and the sacrum. Now, that became a buzzword for the Amish. And there are people out there who will exploit anyone. And so you'll have some English people who will go take this. And they charge them an exorbitant amount of money for it. And they'll go take this weekend seminar—you can go to one ... and on Monday you can go out and call yourself a cranial-sacral therapist.

Cranial-sacral therapists disagree on the titular merger just as stringently. “I am not a chiropractor,” one told me:

We focus on the hydraulic system surrounding your brain and, you know, the whole spinal system. It's not necessarily on how your spinal bones and cartilage are aligned and whatnot, because that fluid has to be flowing well. It only makes sense that if this system is not flowing well, your body can't do what it needs to; it can't heal itself, it can't help but getting sick because it is blocked. Once restrictions in your fluid are released through therapy, your body can fully connect and be the amazing machine it is. You won't need medicines or hospitals because your body will do the work for you.

Despite the protests from licensed chiropractors and the demurrals from cranial-sacral therapists, many Amish, focusing on the similarity of methods and movements, refer to any of these types of practitioners—those who physically touch, move, and manipulate the body in various ways to promote healing—simply as chiropractors. Amish patients also seemed to resonate with other aspects of similarity. It is the case, despite methodological and structural differences, that cranial-sacral therapy and chiropractic methods are both based in a theory that the human body

¹⁰³ Most Amish that bill themselves as some sort of health practitioner are reflexologists, burn specialists, detoxers, herbalists, or naturopaths. They are discussed in the “homecare” category below.

has a point of homeostasis and is fully capable of diagnosing and healing itself once returned to that state. They are also both based in the correction of misalignments, blockages, subluxations, lesions, restrictions, or obstructions, depending on the methodological choice of the practitioner.

All of the cranial-sacral therapists I spoke with in the Lancaster area mentioned that their work stems from a theory of osteopathy originating in the 1930s and then refined into cranial-sacral methods by John Upledger in the 1970s—all were proud to report that they were from the Upledger school of thought, and this issue of homeostasis is indeed at the center of Upledger's work: "Each patient's body contains the necessary information to uncover the underlying cause of any health problem. The therapist simply communicates with the body to obtain this information and help facilitate the patient's own self-healing processes" (Upledger 2005:160). In chiropractic work, this homeostasis is often related as the product of "innate intelligence," of the human body springing from traditions of *vitalism*. "Vitalism is that rejected tradition in biology which proposes that life is sustained and explained by an un-measurable, intelligent force or energy" (Keating 2002:4,6).

These foundational theories of care and healing are interesting when considering why Amish use chiropractors and other body-adjustment therapists to the extent they do. One of the most common responses I got (from Amish and English alike) upon explaining that I was in Lancaster to study Amish healthcare was the following joke: *How do you get an Amishman to take a trip to the moon? ... Put a chiropractor up there*. This is usually followed by something along the lines of "they'd build a pneumatic powered rocket ship," or "they'd train some horses to fly."

Chiropractors are indeed a favored form of primary and preventive care; they are often used as first-line practitioners no matter the symptoms. Chiropractic care enjoys a multifaceted

convergence—a perfect convergence, if you will—of factors that contribute to its overall popularity in Amish communities. First, chiropractors often operate as single practitioners or in small offices with little or no support staff and one chiropractor will frequently serve every member of the family regardless of age or gender.¹⁰⁴ Because of this, Amish families form bonds with them. Combined with the relative frequency of adjustments, the chiropractor provides a continuity of care that is uncommon in medical settings and unheard of in hospitals. Chiropractic care generally costs less than biomedical care and in some cases costs less than care from an herbalist or naturopath. Many in the area run specials for treating the whole family. Parents pay full price but the children are adjusted at a drastically reduced cost—sometimes free or equaling one dollar per each year of age.

As with all of the strands in their pluralistic system, cost remains a surprisingly large factor but is often overshadowed by non-economic factors in discussions and interviews with Amish families about why they choose certain kinds of care. Body manipulation is certainly seen as a more natural form care or healing. Chiropractors and cranial-sacral therapists talk with their patients about the body's ability to heal itself and often connect vitalism's concepts of intelligent forces and energy to the power of a healing God. This is how it was explained by a home-visit chiropractor working throughout the east and south of Lancaster County:

Anybody who does something that's more natural... is working on the body from the inside out. A medical doctor works from the outside in. So it goes along with their [Amish] faith belief in that... the power that made the body, heals the body from the above down, inside out. And that's why they're going to use a chiropractor because they're using it to affect from the inside out. As opposed to ... using a drug. There's a very—drugs are very hush hush, voodoo, voodoo. ... it is because it goes in line with a

¹⁰⁴ There seems to be gender issues on both sides of the patient-practitioner relationship in the case of Amish chiropractic work but female chiropractors always claimed that they had an upper hand treating the Amish because so many Amish women would not be comfortable being touched by a man and would not be comfortable allowing a man to adjust their children. Dr. Joanne Daniel noted her upper hand as a woman competing for Amish chiropractic business and added: “And so as a woman, I'm very safe, you know, I'm a very safe person. On the flip side ... I adjust a lot of men but... a couple... would sooner die than have a woman touch them.”

more natural God-given; if I'm taking primrose, it's from a flower! God created that flower. If I'm taking Zoloft, it isn't from a flower, and—it's from man. And so that's not, that's not gonna be nearly as well received ... when you go to a medical doctor, you give up your power.

As God made the body, God's knowledge empowers the body to heal itself with the right adjustments from a gifted craftsman. As mentioned above, the craft practice inherent in certain forms of medical care¹⁰⁵ seems to move the Amish toward particular modalities. Chiropractic care is very tactile; it involves literally working the body with ones hands. While the adjustments might be impacting unseen energy flows or blockages, the work itself can look and feel incredibly demonstrative. This renders the Amish body a kind of unauthored object in itself—utilitarian while both part of and representative of a cohesive whole.

Many of the licensed chiropractors I talked to had an office/clinic based practice and a small handful did home visit work (either solely or in part). Many also fell into the category of what is referred to in chiropractic circles as “mixers”¹⁰⁶ as they tended to incorporate other treatments such as massage, herbal remedies, x-rays, biofeedback, and even medical referrals. In addition to regular maintenance and trauma care, some Amish even use their chiropractors as triage nurses; a call to the chiropractor may offer some advice about how urgent the problem is, what kind of doctor to go see, or a place to seek help to quell a problem with the hopes that it might not get worse. One licensed chiropractor noted, “I am the person who, when they have a healthcare question, nine times out of ten they're going to call me first and then I can direct them in the proper direction.”

Talking with an array of body manipulators—from trained chiropractors to cranial-sacral

¹⁰⁵ See chapter 5 for more on craft practice and medical technology

¹⁰⁶ For explanation of the difference between the majority “mixers” and the minority “straights” in chiropractic care, see (Kaptchuck and Eisenburg 1998:2217-2218). In short, “straights” are traditionalists that rely only on spinal adjustment to treat disease and believe that is the only necessary focus for holistic treatment; “mixers” incorporate other types of adjustments and models of care to and believe this hybrid offers a more holistic treatment.

therapists with little or no training whatsoever—I learned that their willingness to refer or recommend Amish patients to biomedical services followed along the same spectrum. Those with more formal education and state licensure were more ready to admit that they referred people into the medical system at times. But those explanations were often clarified by making sure they saw the patient to take a crack at the problem first. I asked all of the practitioners I interviewed what they do when Amish mothers call them about treating a pediatric ear infection. Over three-quarters of the licensed chiropractors I spoke with indicated that they would treat the infection and simultaneously try to ascertain its severity. If severe enough, they would refer to a physician; Dr. Daniel, for example, noted that she carries cards of a local otolaryngologist just for this purpose.

These chiropractors typically claimed that they may be able to impact the misalignment that has caused the infection, lessen the severity, and perhaps prevent future problems, but may not be able to clear a festering infection itself. This stands in line with a national survey where 77% of licensed chiropractors claim their interventions improve otitis media (MacDonald 2003). A minority of the licensed chiropractors and all of the cranial-sacral therapists, claimed that they would both improve and be able to fully clear an ear infection using their own methods. These and other pediatric complaints were of particular interest due to the necessary involvement of baptized Amish parents as decision-making proxies for the health of their children and on behalf of their *Gmay*.

Barbara and Frank Frey run a small dairy operation north of Strasburg. The farm has passed through Frank's family for generations and now the Frey's live in their renovated farm house with an empty *grossdawddihaus* on one side and a cousin's family in a cottage down the lane. On a bright spring afternoon the wailing of an unsettled infant diffuses through the kitchen

door and down the front porch. Baby Sarah cries, propped on Barbara's shoulder, and scrunches her red face beneath a delicate cotton cap tied below her chin. Barbara, an experienced mother, does not betray much in the way of being riled; she bustles around the kitchen, expertly maneuvering through small chores with only one hand as only the mother of an infant can. Once we sit for tea—green tea mixed from a powder—Barbara concedes that Sarah's crying has been a bit excessive. But she's not worried because the "baby chiropractor" is on her way this afternoon.

As it turns out, Dr. Joanne Daniel is not the only chiropractor in the area referred to as "The Baby Chiropractor," but she has taken care of the Frey's entire family on a monthly basis for a few years. A licensed chiropractic practitioner, Dr. Daniel's practice consists almost entirely of house-call business and the vast majority of her patients are Amish families. As she does with the Frey's, Dr. Daniel serves the entire family for many of her clients. Sarah calms a bit through our tea drinking and soon Dr. Daniel comes clunking across the porch carrying her portable table for adjustments. She knocks and then lets herself in after meeting Barbara's gaze through the door glass; her head tilts in sympathy as she gently drops the folded table and her heavy tote bag by the neat lines of black boots. She sweeps little Sarah from Barbara's shoulder, "Little one, let's get to you. Let's get to your sweet troubles."

Dr. Daniel does not need the table to adjust Sarah. Being obviously gentle, she holds the baby on her own shoulder and walks her fingers up the baby's vertebrae from tailbone to skull. She grips Sarah behind the ears and around the back of the head with two fingers and stretches slightly while setting the baby supine on the couch. It's hard to tell that much manipulation is being done at all, but Dr. Daniel goes through a series of motions that resemble a cross between a body massage and a pediatric exam. There is some light pulling, some slow stretching, and some

bending around joints¹⁰⁷. “It’s the colic. And she’s tight¹⁰⁸,” Barbara explains. Dr. Daniel asks Barbara a series of questions about Sarah’s feeding habits, what she sounds like when she’s nursing, how often she nurses on each side, and when the crying starts relative to when a feeding ends. The dialogue starts to sound like a meeting between a new mom and a lactation consultant but soon Dr. Daniel (who has the baby resting on her lap) points to Sarah’s face with her small finger. “You see her jaw? Her chin is not lined up.”

Dr. Daniel continues her work for a few more minutes and hands me Sarah to tend while she sets up the table and gives Barbara her adjustment in the next room over. Two of the older kids come in from outside for their treatments and Frank comes in as well to get adjusted and take a lunch break. By the time turkey sandwiches with home-canned tomato soup are served around the big table, Dr. Daniel has adjusted the whole family—talking to Barbara about some postpartum complaints in her shoulder and lower back, talking with Frank about his recurrent issues with popping in his right hip, and working for a bit of extra time with one of the older children who has been complaining of headaches and earaches. Apparently soothed, Sarah coos and nurses promptly. They make plans for Barbara to call with a report on the baby soon and she adds that her cousin is having some troubles with an overactive two-year old. “You tell her to call me,” Dr. Daniel adds, “we can try and bring that boy back into balance.”

¹⁰⁷ Later, Dr. Daniel tells me, “it’s only light touch [with babies] ... in body work, if a baby’s crying, there’s something, you’re doing something that’s—I’m just gonna say it—wrong. It’s all light touch.” She continues by explaining that she can tell when a reflexologist or cranial-sacral therapist has previously seen a baby because they are scared of being manipulated, scared of the pain. She explained, “a baby’s body will speak to you. It will say—that’s enough, you know? Or a breath is a very easy way for me to know I’m done. A baby will take that big breath, resetting the whole system. And so you know, okay I’m done, thank you! Thank you for letting me know I’m done. Whereas those reflexologists, a mom will say, ‘you know I could hardly stand it, they just screamed and screamed and screamed...’”

¹⁰⁸ Multiple chiropractors mentioned the Amish diagnosis of being “tight.” It equates to a hypersensitivity, a fussiness where they nurse poorly or exhibit particular habits like head throwing or not wanting to sleep in a supine position. Being “tight” seems to go hand in hand with being colicky; the two categories seem to overlap but are non-synonymous.

Homecare

The category I call homecare refers to practices within the geographical boundaries of the Amish community. Homecare includes a wide array of weapons in the arsenal (excuse the patently un-pacifist metaphor) for dealing with the body: herbal medicine, homeopathy, detox regimens, other home remedies, reflexology, burn care, and supplements. Family members, members of the Amish community, and local naturopaths administer most of these categories. Occasionally, English reflexologists or herbalists living in the area work with the Amish, but homecare practitioners are much more likely to be Amish than practitioners of any of the other strands, and Amish families in the Lancaster area will more readily trust an Amish reflexologist or naturopath. Many of these modalities are used for general preventive care, acute care, and very often in combination with other strands from the plural system.

During breakfast preparations early one morning at Barbara Frey's house, her twelve-year-old daughter, Barbie, descends the stairs complaining of a painful ear. Little Barbie would be off the hook for enduring school with an earache, but a crisp autumn Saturday means a full day of errands to run. After a quick inspection and a bit of tender sympathy, Barbara directs Barbie to wait on the couch. As breakfast preparation rolls right along, Barbara grabs a bulb of garlic and an onion from a basket hanging by the pantry. She cuts the onion in half, and sets it over the heat in a small saucepan with water. The entire head of garlic gets chopped finely, half put in a little cup with olive oil and half left on the cutting board. Reaching far to the back, a tussle with glass bottles chimes from inside a cabinet next to the sink and one vial emerges between Barbara's right thumb and forefinger. She pulls a few pieces of toast from the oven, slathers them with butter, and transfers the huge amount of raw garlic from the cutting board atop one piece. "Come eat your toast," she calls out to Barbie, "and then we'll tie up your ear."

Barbie does just that—she trundles grumpily over to the table, eats the intense amount of garlic in silence, and then retreats back to her book on the couch a few feet away. Barbara pulls a strip of clean cotton cloth from a drawer and approaches her daughter with the warm onion and the glass bottle. She puts mullein and garlic oil drops from the bottle into the painful ear. Barbara had purchased the drops at a local herbalist but declares that she makes it herself from time to time. Taking a large piece of the warmed onion out, Barbara places it partially inside the opening to the ear and then places a flat circle of onion on top of that. She holds the stacked onions to her daughter's ear by tying the strip of cotton gently around her head. Barbie remains on the couch quietly for the rest of breakfast and after things were cleaned up in the kitchen, Barbara re-warms the unused onion and changes it out for the cold one. Later, as we leave the house headed out to shop, Barbie cracks a smile with a small bit of cotton stuffed in her ear and adds that she already feels better.

It is rare to get people to talk about these types of methods explicitly. An Amish mother would tell me that Amish don't "do much for our health really" and then, over the course of conversation, would mention that her kids take daily oil capsules, they take daily multivitamins, she makes herbal tinctures at the onset of illness, everyone drinks treated alkaline water, and she sees a well-known reflexologist across town regularly. This was all in addition to the chiropractic visits every eight weeks for the entire family and the rare encounter to a doctor for stitches or other emergencies. In talking to Amish families all over the Lancaster area, a notable spectrum emerged with families constantly ranking themselves as to how much of their health is cared for in the home setting. But instead of outlining the home care explicitly, these points were often made by directly contrasting home care to biomedical attention. Some might point out, "I've never been to a doctor, our people take care of things ourselves," or "Some of the children never

remember being at the doctor ... we do most of the things just at home.” Even in our small quantitative study, potentially biased toward the biomedical-friendly, over 10% of adults had never been to a biomedical practitioner in their lives. Many indicated only going a couple of times. Some families may be quicker to call a doctor, although in my study I did not encounter a single family that uses physicians for well visits. The only exception to that trend would be families getting ongoing care at the Clinic for Special Children¹⁰⁹.

Some of the most accessible information I gathered on use of herbs, homeopathy, and homecare preparations in Amish families came from mothers offering me direct advice for my own care or that of my daughter.

- A family that has kids coming in from Amish school in *that* district watches your child? Another family there has a reputation for bringing in lice; be sure to put Melrose compound oil and lavender oil on her hair part to prevent any lice from jumping over to her.
- Your toddler suddenly plagued by a diaper rash that you can't get rid of? Oregano oil, she may smell like pizza sauce but it kills yeast. And here, try this (unmarked) cream¹¹⁰ I got from my midwife.
- If you start adding vinegar to your hair now before it gets too grey, you'll prevent the color from changing.
- Don't suppress a fever; that is God's mechanism for fighting off illnesses. Just wipe her down in aloe vera. Or, wipe her down with apple cider vinegar in the bathtub. Or, put her feet in a tub of apple cider vinegar and place a washcloth soaked in vinegar on her forehead.

I never attracted more of this kind of advice than toting around a toddler with an obvious ear infection at a mud sale¹¹¹. All morning long it seemed that Amish friends could detect an ear-tug at five hundred yards. They stealthily descended with advice. Unsolicited recommendations

¹⁰⁹ In fact, some of the families *most* exposed to biomedical models are those with children seen regularly at CSC. Their relationships with medicine may be a special case indeed, as discussed later in chapters 4 and 5, but there is no doubt that many of these Old Order families interact with doctors and hospitals on a monthly basis and may take up CSC-prescribed biomedical forms of treatment daily.

¹¹⁰ Unmarked cream worked, by the way.

¹¹¹ Mud sales are fundraising auctions and sales held all over the area. Many occur in the spring or early summer. Depending on the size, they may have multiple auction blocks and most sell a large amount of food (to be eaten there as well as goods to take home).

notwithstanding, ear infections were an easy barometer for healthcare in the home—kids get ear infections frequently and they are a localized, specific illness to ask mothers about. As ubiquitous as pediatric ear infections can be, equally universal were the answers all over the Lancaster area. Sadie Graber said she takes a similar measure to Barbara Frey’s when one of her five kids gets an earache. “For earaches I would use vitamin E oil or garlic oil with tea tree oil in; put that in the ear, that almost always works, almost right away. The next morning they’re fine. And put cotton in.” Time and time again I heard the same reworking of such advice: garlic salves, garlic oil, mullein oil, vitamin E oil, tea tree oil, immune-boosting teas, warmed onions, rice bags, and bring down that fever with vinegar.

Many mothers indicated they had learned one technique or another from their own mothers. At first blush, these herbal and homeopathic remedies look like a long-established, indigenous medical tradition. But scratching the surface reveals the vast, fast-moving network of actors and actants involved in homecare. How are new products from Melaleuca, Inc. so wildly popular? What about the constant talk of a putting in treatment systems to make water more alkaline? Why were Amish living hours away from the heart of the old settlement citing the advice of Lancaster County’s well-known Amish herbalist, Sarah Glick, as truth? What are the mechanisms driving this homecare strand of plural medicine?

To start, face-to-face recommendations and testimonials spread through the community constantly—from running into a neighbor, or visit-Sundays¹¹² or any array of gatherings where community members get together for fundraising, quilting, building, repairing, farming, singing, harvesting, cooking, canning, weddings, and the list could go on. Amish health networks are activated by shared, experiential community knowledge around health and illness; the propulsion

¹¹² The “off” Sundays for church are typically used for restful visiting with extended family or friends.

of a given product or service through the network of Amish homecare owes its efficiency to word-of-mouth marketing and personal testimony in a community that remains in constant contact with one another. Events and the structure of constant social interaction are designed to build, laminate, and reinforce a stable *Gmay*. Subsequently, news travels fast, as they say.

But a flow of influential information moves around the settlement and over time in other ways than just intergenerational and oral transmission. Amish across North America read a large number of local, regional, and national periodicals written for and often by their communities: newspapers, church newsletters, circle letters, magazines, community newsletters, devotionals, and more. *The Budget* and *Die Botschaft* are two of the largest circulating weekly¹¹³ newspapers—in 2013 *The Budget* had a reported 18,000 subscribers and *Die Botschaft* 12,000 subscribers (Ansberry 2013). Historian Steve Nolt estimates the actual readership for both papers combined at about 100,000 (2008:195). *Die Botschaft* is published out of Pennsylvania, and *The Budget* is published weekly out of Ohio in both a regional and national edition. These are not newspapers as the English might recognize them. There are no photographs illustrating news stories, no journalists or paid writers, and no scintillating headlines above the fold. Sometimes referred to as correspondence papers, Amish newspapers are constituted by short letters submitted by those in the community. Writers for a newspaper are referred to as scribes¹¹⁴ and most submit regularly; *The Budget* currently has over 800 scribes on its rolls and publishes about 500 letters each week (Ansberry 2013). Contemporaneously, these newspapers operate to circulate news, advice, and solicitations quickly through an analog society. As archives build, they have become a remarkably rich history of Amish communities across North America. *The*

¹¹³ Another popular newspaper, *The Diary*, out of Pennsylvania, is published monthly.

¹¹⁴ While not paid, per say, most scribes get a free subscription and a packet of stamped envelopes to submit their letters.

Budget has been in continuous publication since 1890¹¹⁵ and the more conservative *Die Botschaft* since the 1970s.

Nolt draws a comparison between blogging or individual diaries and the collective diary created in an Amish correspondence paper. Just as a personal diary or blog may be used by to “impose order” on the otherwise disorderly mix of everyday life and make sense of life’s diversity, the correspondence paper does the same for the Amish community at the collective level. The content and context of these public diaries present a “consistent collective life” (Nolt 2008:184-187). In that presentation floats the relentless repetition of unending topics: the weather, how the crops or gardens are faring, who hosted church (or other community events, such as a wedding), who attended said events (particularly those who traveled far), and health. Illness and health are constant fixtures in the pages of these newspapers. Some letters simply address a disease that has brought suffering within a church district. Others go on to detail regimens, assumed etiologies, efficacy of treatments, or advice for those facing similar symptoms. The vast majority of scribes mention something about health or illness from time to time, but some scribes certainly take it up as a favored topic. Alongside the thick blocks of text in these newspapers run advertisements. Many of these are also health-related: ads for supplements, ads for practitioners, and ads for clinics both locally and south of the border in Mexico. Advertisements or letters may also contain information about upcoming health-related seminars being sponsored by a clinic or practitioner in the area.

In addition to the advertisements and accounts of health written by scribes, newspapers also contain regular letters submitted specifically to address issues of wellness and disease.

¹¹⁵ See (Nolt 2008) for a brief history of how *The Budget* morphed from a local paper in Sugarcreek, Ohio, to a primarily Amish publication that is distributed nationwide. Currently, the scribes at *The Budget* mostly come from Plain churches but not all are Old Order. *Die Botschaft* is more squarely Old Order and picks up both OOA Amish and OOMennonites. Nolt notes how this reconstitutes a larger Anabaptist identity among the OOA Amish by aligning them with their Mennonite counterparts and thereby reinforcing identity formation in “Old Order terms” (2008:194).

Amish herbalist, Sara Glick, has a regular space in *Die Botschaft* where she outlines treatments and cures for various ailments on a weekly basis. She also recommends products, announces seminars, and touts the benefits of methods she has come to believe in. Glick's advice was invariably mentioned when Amish talked about certain treatments. "You can read anything Sara Glick has put in *Die Botschaft*," one Amish woman noted, "... it's interesting to me and a lot of people read *Die Botschaft*, you know? A lot of people follow that advice; she's had years of experience, she's in her 80s or something." Glick takes her reputation seriously and thoroughly vets any new product or concept she might decide to sell or endorse. She's even been known to travel and visit factories or suppliers to confirm certain claims about production. Salesmen hear that once she's on board, she will move a lot of their products, so Glick gets constantly approached by would-be supplement companies or others hocking health-related wares.

The kind of collectively-based expertise that raises out of correspondence news and word-of-mouth is the central source for health-knowledge in the *Gmay*. This is just the kind of learning that occurs "through centripetal participation in the leaning curriculum of the ambient community," that typifies a community of practice (Lave and Wenger 1991:100) of the sort constituted by the district. In other words, both the pedagogy and content are shaped at the community level when learning about health, biology, wellness, and disease. The *Gmay* provides a stark example of a context in which these kinds of topics are quite intentionally removed from formal instruction. Just as the body is understood as interconnected with the spirit in this world, the body will not be severed from spiritual experience to be instructionally dissected in scientific discourses on health.

The curriculum in Old Order Amish schools¹¹⁶, by design, contains virtually no scientific or biological education. While the connection to a natural world gets emphasized in many parts of community life, details of biological functioning or empirical discovery found at the heart of biomedical discourses on health are virtually absent. Science education in school, if it can be called that, usually focuses some on the physical world and some on the physical health of the body. Students may learn that insects have six legs or to diagram the parts of a grasshopper. Much of this rote learning relates to farming, working outdoors, and living as good stewards of the land (Ediger 1998). Both lessons executed by a teacher and those read in Amish textbooks are often tied into biblical teachings and scripture passages. As kids get older, they will learn more about the human body, nutrition, and general cleanliness—much of the same information that an English student would learn in a middle school health class. These topics are often the extent of “science” education¹¹⁷. As Karen Johnson-Weiner points out, this kind of Old Order curriculum is not really science education at all because it teaches nothing about the scientific method, hypothesis testing, or discoverable systems. Instead, these curricula reinforce four areas for children being trained in these communities. They convey a limited amount of practical information on the natural world and human body; they “reinforce community standards of cleanliness and hygiene”; they teach about standards for food gathering and preparation within their communities; and they “reinforce social standards of behavior” (Johnson-Weiner 2007:187).

¹¹⁶ Like most North American Amish, the Lancaster Amish schools encompass grades 1-8. Schools are typically in one room with a single teacher, and the school board sets the curriculum. Each district establishes a school board or it may be formed by more than one district if many feed the school. Amish teachers are Amish. They are usually young single women and thereby only require an 8th grade education. The Amish have been exempt from compulsory public education since the early 1970s (see: 1972 Supreme Court decision, *Wisconsin v. Yoder*). For more on schools and education, see (Fisher and Stahl 1986) and (Johnson-Weiner 2007).

¹¹⁷ For many in the Lancaster County area—even basic health lessons are considered useless and are not part of the curriculum in more conservative Amish groups like the Swarzentrubers (Johnson-Weiner 2007:79). Johnson-Weiner’s observation that progressive Old Order Amish, like those in Lancaster, start with school-readiness skills with young children at home (2007:226) was clearly evidenced during my time in the field. In addition to being read to, many children in families I met with had “play” school areas in the house or a desk where a parent may do small lessons with children.

The lessons are always tied into the natural world as being a product of God's powerful knowledge.

The absence of science education could be analyzed as a vector toward the relatively low use of biomedical intervention—without the bias of scientific understandings of human bodies, Amish are more likely to pick and choose from various strands in a plural system. The absence of science in school could also be analyzed to account for all of the potential choice that Amish patients make among various practitioners—those that align more easily with Amish discernments of nature and those that utilize models incongruous with those discernments. These are both interesting lines of inquiry, but when asked outright about absence of science education, what Amish and English alike emphasized was that Amish pedagogical styles steer Amish youth away from questioning skills and toward a high level of trust in others. Amish consultants tended to characterize this in both positive and negative ways—even going so far as to describe Amish as gullible and overly trusting. As one mother who can count on one hand the number of times she's talked to a doctor for her or her kids stated it:

And with the Amish, you know they just fall for everything (laughs). You know, (laughing), anything that uh—but there again, you know if people are searching for something, if they have health problems, they will of course go for something a lot easier than if they feel good all the time.

An older Amish woman with grown children who has worked as support staff in a pediatric practice for many years put it this way:

I tell [Amish] people, 'you ask questions, it's your body. But do your homework. Don't just go to a Rachel Smoker¹¹⁸ and take everything she sends, tell you to, and then go to a medical doctor and tell me that you've done your homework, you haven't!' ... Word of mouth—I don't think [Amish] they do the research like they should. I think they should but I don't think they have the knowhow. They don't know where to look. They don't have the resources and they don't know where the resources are.

¹¹⁸ Rachel Smoker and her family are well-known local Amish naturopaths.

Nonetheless, the kind of trust these women are speaking to does not get extended evenly.

Descriptions of word-of-mouth recommendations and placing trust in what someone tells you about health or treatments are often tempered by a clarification that Amish will trust Amish first.

Again, from the same two women quoted above:

I can't think of someone in the Amish community that would be doing something just to make money off of a product. You know, it's not really the type of people we are. If it helps someone then they *can't help* but share it with someone else who they know is sick. And I guess it's because, yeah, we trust each other. ... even for me, if a salesman comes to my door and he's not Amish, automatically I don't trust him (laughs)... I've had people wanted to sell me cleaner for this or that. They wanted to show me what it does, and I just don't trust people like that. I guess because, um, you know I've heard stories about people like that; who buy their things and its not worth anything.

An Amish person, naturally enough, is liable to trust another Amish person. And if this Amish person tells someone... that he really liked that doctor...that's impressive. Word of mouth is very important because, like I said, they trust each other. They may not trust you because they don't know you. They'll listen, but they may not necessarily trust you. But they'll trust each other. So they'll feel like if someone else tells them about this place, then it's probably worth looking into. Word of mouth is very powerful in the Amish community. It's funny because people think that because we don't have radios or television, that we don't know about stuff. But it's funny because Amish people read. Amish people read a lot! Sometimes they trust what they read more than they probably should—like the paper for instance! But they read a lot.

English consultants were more likely to tie trust with an absence of questioning behavior and an absence of scientific education. One chiropractor who works exclusively with Amish patients put it this way:

You don't ever challenge ... They don't ever question what their parents say, they don't ever question what the teacher says, they become little machines. You put your pennies down for grace.

This chiropractor went on to point out that she thought the lack of questioning learned via education and parenting even extended into spiritual life. She construed the tradition of silent prayer among the Amish as a mechanism to keep children from seeing anyone questioning God or asking God for anything. “And so, how does that child really ever know unless they're taught?

So they just don't question.”

Whether it is a high level of trust, gullibility, lack of scientific knowledge, or lack of questioning, the Amish are a large, stable market for the proliferation of health-related product franchises and equipment sales. In Lancaster, once a home care procedure or product gets an endorsement from Sarah Glick or gains traction in the market, it will spread like wildfire. Light the spark of the Amish informational machine, and off it goes. For example, multi-tiered schemes with business models based on this kind of networking are not uncommon. Supplements, cleaning supplies, and immune booster products from Melaleuca Incorporated¹¹⁹ are quite popular as are similar products from the Shaklee Corporation¹²⁰. Both of these are multi-tiered companies, better known as “pyramid schemes,” where individuals become salespeople and then profit from building a base of people to then sell products on their team. Expectedly, these products appeal to Amish families because they are marketed as natural alternatives to cleaners and supplements one might find in a grocery store.

We're just starting with something, I go for “activate” from Melaleuca. Is what, um, Levina and I have had problems with sore throats a lot in the past years. But as soon as we feel a tickle we take one of those, wait a couple of hours, take a—we really have faith in them, that they work ... It's something you're not to take regularly, it's just like an immune booster ... More and more the Amish are moving towards earth friendly, and you know, more healthy cleaning supplies. (Sadie Graber)

Product lines are sold directly to families via door-to-door sales, community herbalists, naturopaths, chiropractors, midwives, and simply through other friends and family. Most practitioners that also sell herbal preparations combine mixing their own products to sell and retailing lines or products brought in from outside companies. Of those who indicated that they use herbal medicine, almost a third indicated that they buy those preparations from a local

¹¹⁹ <http://www.melaleuca.com/>

¹²⁰ <http://www.shaklee.com/us/en/>

herbalist. 11% indicated that they self-prepare all of their herbal medicine at home while just over 60% indicated that most of their herbs are bought pre-prepared in health food stores,¹²¹ or other retail settings.

Two of the most mentioned trends in this fast-moving network of collectively-based health expertise during the time I was doing fieldwork were alkalizing water treatments and the burn treatments developed by John Keim using salve with burdock. Water treatment systems stem from a pH theory of bodily care: an acidic body, usually determined by testing the acidity of the urine, is a hospitable environment for many states of illness and dis-ease. For example, acidic cells allow cancer to proliferate, acidic environments inflame psoriasis, acid in the gastrointestinal system leads to dysfunctional absorption of nutrients, and musculoskeletal acidity exacerbates arthritis. Popularity of the pH theory is certainly not limited to the Lancaster Amish, but local herbalists and naturopaths have picked up on these ideas and launched them into the network of collective health expertise. Sarah Glick is well known for her support of alkaline water treatments and refers to pH theories frequently in her letters to *Die Botschaft*. According to this system, the alteration of drinking water should be a chief tactic in adjusting the pH of the body. Some use pitcher filters to tweak the acidity of the drinking water in their homes. It happened with remarkable frequency, however, that an Amish person would mention or demonstrate newly installed filtration systems piped right into their kitchen sinks and other areas of the home. Some of these systems, like those sold under the name Kangen¹²² or Jupiter,¹²³ are sold through multi-level-marketing (ie. pyramid schemes) like other products mentioned above

¹²¹ Amish grocery stores all over the area carry these kinds of products. Some have small sections with limited product choice. Others, like Miller's Natural Foods in Bird-in-Hand, PA, have a full selection of preparations, teas, oils, and herbs as well as some ingredients and supplies for home use. Miller's is well known as the "Amish Wholefoods" and focuses on stocking only organic items.

¹²² <http://kangenalkalinewater.net/kangen-water-machines/index.php>

¹²³ <http://www.jupiterionizers.com>

and many of these systems run into the thousands of dollars. Most of these involve an ionizing process that uses electrolysis to give the resulting water a pH reading on the alkaline side of the scale. This water is then understood to directly impact the pH levels on the organ, circulatory, and cellular levels. After getting their new system installed, Sadie Graber explained her motivations for trying out the new water:

Water is so important. I had a problem with that for years, I had psoriasis, have psoriasis ... We actually just put a water system in last week of the ones that you could turn the water up to whatever pH that you want. You can test it with a little tester and it has little buttons there too [pointing to kitchen sink]. You're supposed to start out with 8.5, and then, if your body can handle that without getting diarrhea or sick you can step it up after 2 weeks.

My sister, Joy, she had one, she had a very low pH too. I could never get mine above 5.0 and that's really acidic. I had test strips that I could use to test my urine. I was actually doctoring with Dr. Lacoff; I guess it wasn't, he didn't have the doctor title. He was a reflexologist... and I was taking supplements ... just doing other things to try and keep it away, took cellulife, take cellulife too. And that worked if I take a lot but as soon as I slacked back, you know it went! So yeah, I'm hoping this [new water system] will—Joy said it changed her pH in, um, 3 weeks ... Sarah Glick really has a lot for that because she says cancer grows in an acidic body. And if you have the body in alkaline, you're body is much healthier.

There was a constant buzz around alkaline water, acidity, and body pH—talk of it in a lot of homes or telltale countertop spigots or pitchers resting next to the sink. And like Sadie, those that referred to switching, trying, or investing in these systems invariably invoked a family member that had tried it first, a recommendation from a practitioner of some kind (usually an herbalist, naturopath, cranial-sacral therapist, or reflexologist), mention of it in *Die Botschaft*, or all three. One midwife talked at length about how these fads come and go with Amish families. In her opinion, practitioners prey on Amish sensibilities by first convincing a large swath of the community that they have a problem that needs to be solved and then offering a way to solve it.

[You] could hear ten, twelve people in a day saying, 'I have an infection in my ovaries,' so by the end of the 1st day, they can understand, they've all been to see this one certain lady who that's her pet for awhile, a year or two. Everybody has infection in their ovaries.

Then it's everybody has parasites. And then you have to buy their very expensive products, over \$100 per bottle ... Now the popular thing is everybody is giving cranial treatments.

The energy behind Jon Keim's burn treatments was considerably different; it had less of a fad feel and felt more like a defining, enduring actant in the network of Amish plural health fields. In some ways, these treatments typify the spread of Amish health expertise, in this case from a genesis within the wider Amish community itself¹²⁴, through rapid systems of word-of-mouth and communal experience. In other ways, these treatments differ from many in the home care field because they are relatively well-regarded with less contention from other strands of the plural system. Burn treatments here are becoming routinized, wide-spread, and considered at times to be a miracle cure surpassing most therapy available for burns in any other health system to speak of. Virtually all of the practitioner types interviewed for this project had some positive comments or anecdotes about the treatment no matter their modality, training, approach, or education. Some, Amish and English alike, expressed skepticism of John Keim's treatments in cases of third degree burns covering large percentages of the body¹²⁵. But for less serious or less widespread injuries, this herbal remedy has caught on as the treatment of choice.

The Old Order Amish are at an increased risk for burn injuries (Rieman et al. 2008) partially due to their use of open flames in home and farm settings. John Keim's young son was badly burned over much of his chest and abdomen by boiling water. After trying other home remedies to immediately relieve the pain, Keim was at a loss for how to help. He was particularly timid of

¹²⁴ John Keim's story is printed in the burn care books that he has authored but it is frequently told and re-told as a testimony to God showing this Amishman a way to ease his son's pain.

¹²⁵ Even some of Keim's own pamphlets suggest seeking evaluation by "a professional." It is unclear what kind of professional this is referring to. *Burn Aid: Written for the Amish By the Amish* is step-by-step instructional pamphlet used in burn treatment training seminars and it makes this recommendation. Over a third of this book is reserved for testimonies as a teaching tool containing tips and anecdotes from other's experience.

the local hospital after receiving letters from relatives far away detailing their own child's painful ordeal in a burn unit. About to run out with the team for more gauze, he turned instead into the woods for a brief walk "to think and pray." His mind took to thinking about an alternative to gauze that would not stick to an open wound.

I thought of how God create the Earth. I honestly felt He kept the poor in mind while Earth was being created. If that were true, the people living on islands without hospitals and drugstores should also be able to find necessities for their needs. And since even such primitive people had fire, they also would have burns. I tried to think of all the things a man might find on an island to help treat such burns. I thought of water, mud, rocks, bark, wood, leaves (Keim 1999).

After gathering some slick plantain leaves from the woods, Keim returned to the house, applied a coat of BFC salve¹²⁶ to the wounds, covered them with the leaves and let it sit. They supplemented the child's diet with juices, extra fruits, and extra vegetables. The family re-applied the treatment twice daily and by day five the wounds were covered with fresh skin (Keim 1999).

After the success with his son, Keim began treating others and refining his materials. He developed a new ointment specifically to treat the skin for burns or other similar kinds of injuries—the straightforwardly named B&W ointment, or Burns and Wounds Ointment¹²⁷. While many of his publications recommend that the specific salve and leaf combinations are flexible, the standard pair considered most effective involves B&W ointment covered by burdock leaves. This treatment is sometimes referred to as "burdock treatment" or "Amish burn care." Open

¹²⁶ It would not be surprising to find BFC salve in an Amish medicine cabinet. Traditionally used, the Bones, Flesh, & Cartilage" salve can be bought pre-mixed or made at home. The recipe is widely available. Suspended in grape seed oil and beeswax, the salve contains oak bark, comfrey leaves, black walnut bark, gravel root, marshmallow root, mullein leaves, lobelia, skullcap, and wormwood.

¹²⁷ B&W shares some similarities to BFC but includes a high amount of honey—a substance known to have some anti-microbial properties. There is only one "true" B&W, the recipe is trademarked, and the Amish tend to buy it instead of attempting to make it themselves. B&W is available virtually anywhere the Amish shop and found in virtually any Lancaster Amish household to be used for minor cuts or scrapes as well as serious burn treatment. The ingredients listed on the B&W jar are as follows: honey, lanolin, olive oil, wheat germ oil, marshmallow root, aloe Vera gel, wormwood, comfrey root, white oak bark, lobelia, vegetable glycerin, bees wax, myrrh.

testimonials about burdock treatment are easy to come by in Lancaster County. In addition to the stories found in the training literature itself, narratives about the pain-free, non-scarring, all-natural treatment given to Keim by God in the wilderness pop up constantly. In addition to regular mention in correspondence papers, a forty-six page pamphlet titled “Plain Interests: The New Concept in Treating Burns” circulates widely and devotes itself solely to letters about the treatment.

The treatment includes the following steps. First, burns should be cooled in water and chemical burns neutralized with baking soda. The B&W ointment should be applied at an eighth-inch thickness all over the burn. Dried or fresh burdock leaves should be de-ribbed, scalded in a water bath at 180 degrees, and then pressed to get rid of excess water. A layer of scalded leaves should be placed on top of the ointment and then held in place with a conforming gauze wrap. Everything should be changed every twelve hours until the wound is completely healed. Keim also suggests a complementary diet to supplement the healing process. After replacing electrolytes and preventing dehydration, he recommends a period when the burn victim takes in freshly pressed vegetable juice taken especially from carrots, celery, spinach, cabbage, and a small percentage of red beets. After the juice phase, the patient should move to “easily digestible” meals like meat broth, eggnog from raw eggs, bee pollen, liver cooked rare, mashed bananas, fruits, and melons of any kind.

On a sunny November afternoon a family comes into the Clinic for Special Children with an eight month old with stalled weight gain, diarrhea, and difficulty eating. Most of the family files into the exam room—mom, dad, the baby, a small gaggle of other kids, and an aunt. The mother sits in a large upholstered chair and reclines with the baby on her chest. The father recounts that the troubles began when baby was about four months old. In that time, they’ve seen

a reflexologist (the baby cringed, they report, when the reflexologist touched areas on the foot associated with the intestines), they've gone for two treatments with a cranial-sacral therapist, they've switched her to formula, and they're giving her "Supertone" herbal drops for the liver.

The physician seeing the family asks a series of paced questions to root out the cause of failure to thrive, to account for ingestion of various alternative elixirs, and to probe for any tie to genetic conditions in the family. He is calm and deliberate, listening to the family describe the symptoms again from different angles, catching new information each time. "And this?" he asks, pointing at the heavy gauze sheath wrapped copiously around the forearm of the baby. "That's for a burn, burdock in there," the father gestures toward the baby. The doctor responds, "it's working?" and with quick nods from the patients, he quickly moves on. Not two weeks later, another physician in the practice sees a toddler with an undiagnosed developmental delay in an exam room. As the tot gets observed and the doctor probes for information about the child's skills, he slips in a mention of the gauzy bandage on the father's hand and wrist that is covered loosely by an old white sock with holes cut in it for the fingers. "You have B&W under there?" he asks. The father indicates that his hand was burnt very badly, "down to the bone, it seemed!" he said, pointing to the area between his thumb and forefinger. The physician replies, "I'll take a look at it, if you want." And the father declines with a smile. He's not worried, he said. He's not worried one bit.

Later, I asked both of these physicians why they did not check these wounds—particularly the one on the patient being examined at the time. Unfamiliar with burdock treatment, I was flummoxed as to why such typically thorough clinicians would ignore such an injury. Both gave me similar responses—"It works. Barring infection, which should be a concern, it works." They'd seen it work on these small-area burns more than once. The clinic's registered

nurse, Christine Hendrickson, picked up and told me her own story of the burdock treatment's success.

My husband did that. He fell in a fire pit. And, I kept saying, this, you know I could see on his hand... —we were at a picnic and the pit was built down and he went to pick up, like the, just get some air in it because it was just kind of smoldering. His foot slipped. He had crocs on and his foot slipped and then he literally fell into it. Trying to get up, [he] fell back again, his cousin came flying over me and I just went like this because I could just see him rolling in this fire because that's what he was doing. And so then when we got in the car to leave I said, "pull up your sleeve." And he did and he had *blisters* all over here and I said, "you need to go to the emergency room." I'm like, "you can't tell me that doesn't hurt," and he's like, "it's not too bad."

...
I knew his mom had B&W and I had heard that people use that. So I went to her house and I got it and we put it on and we wrapped it up. And then the next day he got burdock leaves from my [Amish] neighbor. And we put those on. And he said—when he put those leaves on it was *so soothing*. And his arm is completely healed. We never went to the doctor. Because I was worried, I had [CSC physicians] look at it in here to make sure there wasn't any infection. So, I knew enough to look at that; there were a couple of areas I just wasn't sure about. And so we kept on it, we did it twice a day ... it healed great. Amazing, so I believe in that. ... You would think something sticky like that would keep the burn in, or you know? I don't know, I believe in it.

The nurses and doctors at the Clinic for Special Children are not the only biomedical practitioners putting some faith in burdock treatments. Burdock with B&W has piqued the interest of the biomedical community and some hospitals will allow Amish families to administer the treatments inside a burn unit. This fulfills the health desires of the patients and families while allowing the hospital staff access to monitoring the patient. While no large-scale studies have been performed to date, there is a trickle of evidence from these anecdotal, functional studies that confirm some success. When a burn unit in upstate New York brought in an Amishman with burns on 75% of this body, his family insisted on using burdock treatment. Unfamiliar with the method, they called other burn units in high-Amish areas and found at least one that had seen success with a 35% burn (Kahn et al. 2013:e14). In the end, this study supports Keim's claim that third degree burns, especially over a large area, may need additional

attention—this patient died from his injuries¹²⁸.

I recently spoke with Barbara Frey about a study I read detailing the “assessments of antimicrobial and cytotoxic activities” in the burdock leaves and B&W ointment (Rieman et al. 2013).

BF: What did they find then in that report?

MK: Well, they took apart the B&W, they could not test it up in their machines, so they just tested the components, the parts. They concluded that there is a chance the treatment could have bad affects like spreading infection or harming cells in the body.

BF: So they did not put the B&W and the burdock together on a burn?

MK: No—they were doing this kind, they did this type of study where they test the materials to see if they performed a certain way. They said they could not say how it could heal burns because of how the parts of the treatment behaved in the laboratory equipment.

BF: (laughs) well of course. Of course they didn't. You tell those doctors to not waste time putting B&W in machines and give it to a burn that needs that! That needs that. You can't put a bridle on a fencepost and complain that it's not driving a horse! This is the trouble with all that doctoring—they break things up and don't really look at people as the whole things that God made. And you miss it! You miss it because you're looking at some small part—that bridle, that bridle on the fence isn't the whole team. That bridle is not going to get you to town. Our people know you need the whole team to get to town.

Medical Tourism

The Lancaster Amish take part in well-established routes for medical tourism, primarily to clinics in Mexico. The border clinics in Mexico are numerous and utilized by people from all

¹²⁸ The authors publishing this case study go on to present the ethical considerations made in this case:

Although the Amish may live a simple lifestyle, they have a complex belief system that differs from that of mainstream America. Beliefs may further differ between Amish sects and individuals. Thus, the delivery of medical care also becomes complex and should be tailored to the needs of the individual.

... challenges became particularly evident as the treatment plan of the burn team was not consistent with the family's wishes. These differences were significant enough to prompt an Ethics consult and involve hospital administration. However, this patient was a healthy, young male with a severe but potentially survivable injury. He and his family made a decision that determined his course of care based on the principles that guided their lives. Some might argue that this was a needless death that could have been prevented with modern medical care. However others would say that this death was noble, as a man died upholding the values that he held dear... As physicians, we often become fixated on delivering what we consider 'optimal care', and minimizing morbidity and mortality becomes our primary goal. In reality, the goals of the patient are not always consistent with those of the health-care provider. Regardless of our personal views and beliefs, it is important that we respect the wishes of our patients and preserve their autonomy – even when it makes us uncomfortable (Kahn et al. 2013:e15).

over the USA and Canada, not just Amish and Mennonite travelers¹²⁹. A former health official in Baja, Dr. Alfredo Gruel, estimated there to be as many as 50 “alternative” clinics in and around Tijuana (Isackson 2006). These clinics offer a mix of therapies including biomedical treatments similar to what one may receive at a hospital in the United States, treatments typically classified as alternative or complementary, and other forms of care (including procedures, surgeries, and injections) that may be unapproved or banned by American, Canadian, and/or Mexican health authorities.

Amish trips across the border are usually for dental work, discounted surgery, or therapy for illnesses with high morbidity. This includes therapeutic and surgical interventions for life threatening illnesses such as cancer and other long-term or debilitating illnesses such as arthritis—particularly those that remove individuals from work roles in the community of practice. Prohibited from flying, Amish will hire a van taxi for the travel, take a bus, or ride the train¹³⁰. In many cases, trains and buses will take Amish visitors right to the border; some stay on the US side in motels very near crossing areas. For those staying stateside, regular shuttles run across to Mexico ferrying Amish and other patients back and forth all day. Some motels, like the International Motor Inn in San Ysidro, California, offer these shuttles for free and some offer reduced room rates for those coming to seek medical care across the border in Tijuana (Isackson 2006). This seems to ease the transition back and forth for Amish travelers; going across with regular shuttle drivers lessens the stress at border crossings (Emerson 2002b:1A) and puts Amish

¹²⁹ Literatures support the difficulty in determining how many people from the USA travel for some sort of medical tourism on a yearly basis. One study uses self-reported reason for air travel listed as “health treatment” on in-flight surveys and puts the number at 17% (Reed 2008:1434). This, of course, is a limited measure and accounts for no car or train travel and therefore likely excludes much of the business of border clinics in Mexico. Moss (2005:68) points to the pre-NAFTA years as boom-times for cancer clinics in Tijuana; just two clinics alone clocked 13,000 patients a year coming in for Laetrile (apricot seed extract) treatments.

¹³⁰ For families heading to Tijuana, train travel from Lancaster, PA to San Diego, CA averages about 60 hours.

visitors in the care of drivers and other services that have been recommended by friends or family.

Two of the major categories mentioned when I asked Amish consultants why they might choose to patronize clinics in Mexico were cost and approach to healthcare. Costs are significantly less for many kinds of care in Mexican clinics. Even if including the travel costs, Amish families may pay a fraction of what they would pay for similar procedures in the United States. Lydia Schwartz, an Amish woman who had traveled to Mexico for various medical treatments, was profiled in an Indiana newspaper in 2002. She explained that even though a US physician offered to waive his bill, she declined a hysterectomy in the USA to avoid the hospital bills. She got the operation in Tijuana for \$3000 (Emerson 2002a), a surgery that may have run an average of \$8,375 at that time in the USA (Beinfeld et al. 2002:1302)¹³¹. Mexican clinics also operate as self-pay offices. As cash-pay patients, the Amish do not feel unfairly charged for services as they might back home. This kind of direct comparison of the same procedure can be stark, but it is only one part of the cost of care in Mexico. Many of the procedures are considered alternative to biomedicine and some are novel—no price comparison exists. On these points, Mexican clinics can be seen as quite expensive. Among the laundry list of reasons that detractors show concern for over-the-border treatment, is that the clinics are often categorized as costly. One estimation puts cancer care (unconventional by biomedical standards) in Tijuana during 2001-2004 in the range of \$7,200 for a three-week outpatient course and \$17,000 for a three-week inpatient course (Moss 2005:79).

After that hysterectomy, Schwartz later returned to Tijuana to treat a debilitating pain in her foot where she had suffered an old injury. Citing toxins from the metals in her body, the

¹³¹ Costs quoted were taken from a study performed at a medical center in Boston during a time spanning 1998-2001. Lydia Schwartz would have had her surgery in 2000, traveling from Indiana.

Contreras Clinic in Tijuana removed the metal plate with screws holding her ankle in place as well as over a dozen metal dental fillings. With the rejected metals removed from her body, the doctors told her that in three or four months she would be pain free with a “miracle foot” (Emerson 2002a). Removing known metals, like Lydia’s, via surgery is a common approach to necessary detoxification for healing in many of these clinical settings. This toxin removal is part of a larger system referred to as metabolic therapy—a term often used as shorthand for the holistic approach where an array of specific methods may be employed to remove toxins and simultaneously boost the immune system. This approach can be inclusive of Kelly’s Treatment, Gonzalez treatment, Issels whole body therapy, and Gerson therapy, among others. There are many devotees to these on both sides of the border; some forms of metabolic therapy include methods that have been tested and rejected by the general biomedical establishment in the US but still maintain a popular following. For example, metabolic therapy is widespread enough as a cancer treatment that the American Cancer Society has released information explaining what it is in the context of complementary care.¹³²

Simon Shenk, the Amish man with cancer introduced earlier, took a trip to Reynosa in the Mexican state of Tamaulipas to receive cancer treatments despite the warning from his wife’s sister that he should head to Hermosillo, Sonora instead. She got news from her mother that an aunt living in New Jersey heard that Reynosa and Juarez were more dangerous these days, but Simon’s cousin had been to a clinic in Reynosa. That cousin felt his cancer was cured by chelation therapy. Simon was not sure, at first, what kind of therapy he would get. But he was hoping for chelation therapy too or perhaps Laetrile, also known as apricot seed extract. He

¹³² See the ACS website <<http://goo.gl/26qBBn>>. The concept of detoxing the cells and then allowing the body to reinvigorate itself is contrary to the standard biomedical model. The biomedical model understands cancer to be a disease of cell regulation caused by transformation at the genetic level and impacted by environment; the resulting treatment typically focuses on the location of the cancer and involves removal, reduction, or eradication of the cancer cells themselves.

explained the etiology of his cancer this way:

Toxic—unclean—things and metals in your blood get to where the cancers begin. With those toxic pieces in the way and your body won't heal, cancer won't heal. Take out the things causing the cancer to happen, then the body can get better, feel better, you know, and the cancer can go away. Something you've injected does the work; the trash in your body gets to remove.

Moving his hand away from his chest out in the air as if drawing out an impurity and tossing it toward the trash bin, Simon expresses the paradigm espoused by the metabolic therapy movement; the body falls victim to toxins that have built up from environmental exposure, including through diet. This build-up of toxins can cause any number of diseases. Cancer is commonly linked to this toxicity as are a number of other debilitating issues such as arthritis, diverticulitis, lupus, Crohn's disease, or multiple sclerosis. The resulting treatment involves addressing the balance of the whole body in three ways¹³³: detoxing the problems present in the body, supporting that detox with items meant to boost the immune system, and addressing the site of illness directly (for illnesses that have a specified site, ie. a tumor). The detox phase may include any of the following¹³⁴:

Detoxification Treatment	Description
Dietary regulation	may include macrobiotic, vegan, fasting, gluten free, dairy free, or other restrictions
Surgically removing metal	taking out dental fillings or previously implanted screws, plates, or pins anywhere in

¹³³ There is a spectrum of research on the many individual treatment types involved in this kind of metabolic therapy and literature can be found both in great support of many methods as well as citing studies that show no (or harmful) effects. Although their point of view is guardedly anti-metabolic therapy, The American Cancer Society has created an easy summary of the approach and array of possible treatments included. Many of what are listed in the text come from interviews with Lancaster Amish, discussions with Lancaster physicians about Amish medical tourism, as well as from the ACS list. Their list is available on their page entitled "Questionable Cancer Practices in Mexico": <<http://goo.gl/nQzI9B>>.

¹³⁴ Note that some of these treatments, compounds, or substances are understood to have different properties according to biomedical science but are described in this chart and the site-specific chart below in the way they are conceptualized by practitioners and patients of metabolic therapy. In other words, these descriptions indicate utility in the setting of metabolic therapies in Mexico and/or the use of homecare among the Amish in Lancaster PA. The treatments listed in both charts were compiled from interview data and literature on boarder care in Mexico (Horton and Cole 2011), (Moss 2005), (na 1991), (American Cancer Society 2008), (Emerson 2002).

	the body
Cleanse regimens	lemon cleanse, flushing large amounts of water
Juicing	beets, carrots, liver
Chelation therapy	a chelating agent is injected to encourage the removal of metals from the blood ¹³⁵
Water treatment / pH	putting the body at a neutral or alkaline state by treating drinking water with pH drops, ionizers, or filters
Urine therapy	Urine contains antibodies and when re-introduced to the body (IV, oral, or enema) it will stimulate the immune system to attack and remove toxins
Colonics	removal of toxin build-up in the colon, also stimulates other organs to release trapped toxins; common types include coffee, herbal preparations, cider vinegar

Note that many of these same treatment types are also used in Lancaster under the homecare strand of their plural system.

In addition to detoxification, metabolic therapy calls for intensive immune system or general body support. This typically involves administering combinations of herbs, supplements, enzymes, minerals, vitamins, or homeopathic solutions. Often, a detoxification regimen will coincide with or be followed by super-loading certain compounds associated with the specific disease being treated. Simon recalled being treated with IV vitamin C and high amounts of vitamin D in addition to a regimen of herbs that “tasted so bad—the inside of a trash pile before it burns.” Treatments in this kind of metabolic therapy also include direct attention to the site of illness itself, if there is a focal point. The chart below lists a selection of these types of interventions and how they are described in these treatment models:

¹³⁵ Chelation therapy is approved in the US for heavy metal poisoning but no other therapy. The FDA issued a warning in 2010 <<http://goo.gl/sV1yIm>> warning companies not to market OTC chelators and that these products were making unproven health claims.

Site-specific Treatment	Description
Insulin treatment or Insulin shock	patient repeatedly brought into and then out of a hypoglycemic state via IV-insulin. The insulin allows cells to absorb other disease-fighting agents administered simultaneously
Oxygen / Pressure	extra oxygen allows body to kill diseased cells
Heat	whole body, one part, or specific site (such as a tumor or injury) is exposed to increased heat
Light / UV / phototherapy	Blood may be cleaned with UV light and reintroduced to the body; shining intense UV or colored lights at the body may harm bad cells within
Apitherapy	Honeybee venom is applied via live stings to treat a diseased area
Herbal skin applications	salves, ointments, poultices, and the like containing herbs are used to draw out diseased cells or treat issues on the surface of the skin
Organ or stem cell extracts	stem cells or other cells from animal organs (sheep are common) are injected; organ cells will help heal an analogous diseased organ in the patient
Laetrile (a.k.a. amygdalin)	apricot seed extract via IV injection or orally, releases cyanide in cancer cells but does not harm healthy cells
Cartilage	shark or other animal cartilage stops / slows the growth of blood vessels that feed a disease or tumor
pH therapy	cancer cells grow out of control because of their natural pH levels; oral or IV cesium chloride creates an alkaline state when introduced to combat diseased cells

Like other forms of medical care or bodily interventions, referrals to Mexican clinics come via word-of-mouth evangelism from family members and community members. But clinics in Mexico don't rely solely on the community's ability to spread the word; these practitioners

actively seek out Amish and Old Order Mennonite clientele via newspapers and lecture circuits. In addition to their function as historical diaries and vehicles of first-hand health accounts as discussed above, Amish newspapers are full of small advertisements for clinics, services, treatments, and travel in Mexico. Widely circulating newspapers like *The Budget* and *Die Botschaft*, offer Mexican clinics a venue to reach a large number of potential Amish clients from all over North America.

In addition to spreading the word via newspapers, some Mexican physicians or representatives of a clinic¹³⁶ will speak at lecture circuits, special conferences, or community gatherings. Here, they proselytize for Mexican health-tourism, start face-to-face relationships with potential clients, and spread the message of their particular therapies or specialties. These gatherings often feature a talk and/or question and answer session with the visiting practitioner. But central to the pitch are local former patients who come and give a testimony as to the efficacy of their visit to Mexico. A father-son team, Dr. Adan Ernesto Contreras III and Dr. Ernesto Contreras Jr., run the clinic used by Lydia Schwartz to address the pain in her foot from an injury she sustained in a bad jump from a buggy. These doctors are among the many who travel all over the United States to speak in Amish communities. They visited Lydia Schwartz's community in Adams County, Indiana, as well as placed ads in *The Budget* and other Amish newspapers. In fact, this clinic has become so tied into a Plain patient-base, the younger Dr. Contreras has learned to speak Pennsylvania Dutch as well as fluent English and native Spanish.

¹³⁶ While many are not, some Mexican clinics are actually owned by American corporations. For example, *Centro Medico Del Noroeste* in Sonora, Mexico puts forward claims of “alternative treatment that really works,” on its website and boasts to be “continually developing progressive new treatment strategies that focus on the health of the body as well as the emotional and spiritual wellbeing of the patient . . . medical treatment programs are designed to concentrate on the person as a whole, while at the same time addressing the symptoms of the disease and its causal factors.” It is owned by New Hope Unlimited, LLC, located in Scottsdale, AZ. Some corporate-owned clinics may employ American reps for advertising. One biomedical physician in the Lancaster area indicated that a corporate office in Florida owning a Mexican clinic frequented by Amish has approached him to hold some seminars in PA. They asked if he would “serve as a medical expert in support of the clinic”; in return, he was offered a substantial payment. He declined.

And he also seems to do a very good job at tying his own holistic practices into Amish concerns around perceptions of natural origins and reverence for the knowledge of God found innate in human form. In a newspaper interview, Contreras indicated that his clinic:

...treats body, soul and spirit with prayers, singing and love. American doctors are used to treating only the body ... When you talk to patients and let them know you're human, they understand you make mistakes, and it is up to God to heal. The doctor is a very small part of the healing process (Emerson 2002a).

Midwifery

The muddy ruts in the yard look threatening but my four-wheel drive car has not disappointed through the snowy winter. Plus, there is simply no other choice, given the overcrowded driveway jam packed with cars, taxi vans, and a team or two munching on sparse plugs of new greenish vegetation. Approaching the old, two-story farmhouse from the back, I'm not too sure which door to enter when an Amish boy playing on a side porch points to his left. "*Zimmlich gut. Wie bischt du?*" I ask, quietly. He flushes and giggles, jumps off the porch into a muddy planting area and darts around the side of the building like an elf disappearing into the thick. Turning the small doorknob and stepping across a wide wooden threshold, the air inside hits my face with lavender and cinnamon so strong that I resist the urge to gag lest I make a scene in front of the crowded room that unfolds before me. Lined on two sides with wooden benches, Amish women in various states of pregnancy press close together. Some have a newborn resting on their laps; most have older children near their feet or ribboning through the room between visitors. Due to the chill in the air, the room is suffused with black coats, cloaks, jackets, outer bonnets and all of the dark fabric is dotted by diaper bags and delicate newborns swaddled in multiple layers. Just as I step forward, a woman stands to leave. She pulls with her a large tote bag clinking with over a dozen bottles and containers; she's trailed by two small kids,

fussing with their coats as they head toward the door.

Walking to the desk, I find that the sign-in sheet has a space labeled *husband's name* as the primary identifier for the patients. Scribbling in my spouse's name, I turn on one heel for the empty seat just as a teenaged girl comes around with a cuff and sphygmomanometer. The girl has a small kerchief tied around her hair and she fumbles a bit with the cuff. I find the reading dubious both due to the fact my respiration has been impacted by the herbal fume of the place and by the fact that she leaves the cuff on so tight that my hand starts to turn blue. But after me she goes arm to arm to arm taking the blood pressures of everyone present and scribbling them down on a yellow piece of paper. The women chatter amongst themselves, but the blood-pressure attendant goes about her fiddling with the bulb in concentrated silence.

It turns out that the head midwife and two others are out on deliveries, so a reduced staff of assistant midwives and apprentices handles the whole place. These staff members are mostly dressed in long skirts, some have their hair covered. They mostly appear as a cross between nineteenth century homestead girls and homeschool-blogging attachment mamas. These women are bustling about, opening doors, calling women into back rooms, talking in low tones, and we wait. Wait and wait and wait. We wait so long that I'm sure I'll pass out from the thick, invisible plume of lavender shooting straight up each of my nostrils every time I breathe. Ads on the walls and bottles on the shelves advertise products like "Source of Life Gold Liquid," or "Sovereign Silver Immune Support made with real silver." Another sign reads "Remember: Your half payment is due at 28 weeks." At one point a large cabinet is opened to reveal shelf upon shelf of bottles, jars, and disposable medical supplies like absorbent pads. Rifling through the pharmacy of herbs and supplements, an apprentice tips back a couple of amber bottles for an Amish woman checking out, chucking them into a plastic bag as she reviews what the patient needs to

remember to have on hand at home when labor starts.

Realizing that we're all going to be here for awhile, I ask the woman next to me if this is her first time coming here. "This," pointing to her obviously large midsection, "is my fourth. I've had them all with this midwife at home." Others offer up—2nd, 6th, 9th—all had them with this midwife and adore her. One young woman, bouncing a chipper toddler on her lap adds that this is her first. The woman sitting next to her looks startled, exclaiming, "I assumed he was yours—he looks like you!" The first-timer responds, "He's *mein Bruder!* Mother had all ten of us with the midwife!" When I ask why a midwife, why not go to Women's and Babies, two of the chattier women open up with a litany of reasons. It's natural tops the list, God did not intend doctors to cut out babies, and it wouldn't be right for a man to help deliver a baby like they do in the hospital. The only other English patient in the room adds that this midwife asks a good and honest fee with no boosting up of the prices. "Plus, she delivered *me!*" exclaims the first-timer. An Amish mother of five emphasized the ongoing role that the midwives play in the lives of her and her children:

The midwife versus the doctor, there's such a big difference! I just, oh, it's so much nicer to have a woman doctor and just they way they work with natural things. Like they wouldn't just think you're nuts if you don't want to immunize your children. Things like that, they're much more understanding.

When I finally get called back, the new papers have my husband's name printed boldly across the top with mine written in small letters underneath. I have no idea if the person I am talking to is a midwife, an apprentice, or neither, but she takes a sparse medical history. "Have you ever had an abortion?" she blurts out. I stare back. "Do you ask all of them that?" I say, pointing toward the waiting room. And matter-of-factly she replies, "no, but you're English. And from *North Carolina.*"

The space itself is just another farmhouse room—wide plank wooden floors, tall

windows with good light. There are overflowing bookshelves and stacks of books sitting atop a clearly unused old wooden exam table. A woman sits behind a desk outfitted with some basic medical supplies and I sit atop a long table against the wall at an awkward height. It feels more like a low counter. Everything is a bit dusty. Everything is a bit disheveled. I see the whole space through two sets of eyes. It is at one time a charmingly simple home outfitted to provide basic perinatal care and support women in an enveloping circle of sisterhood. It wants to be that commune space, it wants to be The Farm.

I close my eyes and think about the obstetrician at Lancaster Women's and Babies Hospital that I interviewed a few days before in a scrubbed-down sterile office near suites of advanced biomedical equipment. My mind shifts to thoughts of contention between these types of practice—these unregulated midwives have been sued by the state for practicing without a license. Just as I am about to smile to imagine that OB's shudder at this herb-infused lady-fest, the midwife pricks my finger and startles the living hell out of me.

Most Amish women in the Lancaster area use a midwifery model for gynecologic, prenatal, obstetric, and neonatal concerns. Similar to the chiropractor grouping above, this can be split into two categories: care received from unrestricted midwives¹³⁷ unregulated by the state of Pennsylvania and care received from certified nurse midwives (CNMs) who have received licensure from the state. Attending to a homebirth is not illegal in Pennsylvania, but the midwife must be a licensed CNM that is undersigned by an overseeing physician. Due to these types of regulations, CNMs in Lancaster County frequently attend births at small, Amish-friendly

¹³⁷ I use the term “unrestricted” here to create a category for all the types of midwives that are not licensed to practice midwifery according to the state of Pennsylvania. This includes both midwives with no formal training (often referred to as lay midwives or direct-entry midwives) as well as those trained as Certified Professional Midwives (CPMs). Most CPMs do not attain degree levels but instead receive certification via midwifery programs or completing sufficient hours of apprenticeship, completing official clinical practice under supervision, and finally sitting for a written exam. They are regulated and allowed to practice in 28 states. Pennsylvania is not one of those states. Note that this category does not refer to midwives who are also Amish—this phenomena has died out in Lancaster county and the immediate area; there are no known Amish women acting openly as midwives in the immediate Lancaster area.

birthing centers and occasional homebirths. Unrestricted midwives are far more likely to attend at homebirths but some have also set up clinic or office spaces for pre/postnatal care that include rooms for birthing as a kind of unofficial birthing center like the one I visited that day.

Approximately 41% of the Lancaster Amish primipara births occur at home, ostensibly attended by an unrestricted midwife and/or family member; another 12% occur in a birthing center of some kind (Miller et al. 2007:169) although this self-reported data does not differentiate between regulated centers staffed by CNMs and the small clinic-style centers staffed by unrestricted midwives and their trainees. As of mid-2013, the state's Board of Medicine was considering altering their rules to allow licensure of Certified Professional Midwives—this class of midwives that are trained but do not have nursing degrees. These potential changes are due in part to a history of legal action against lay midwives working with the Amish (Toland 2013, Miller 2013).

Like many of the other areas of healthcare, midwifery care exists on a spectrum from less to more medicalized, or in the eyes of the Amish, more to less “natural.” Many of the strands of their plural system consider the state as a would-be adjudicator of medial authority and this possible characterization becomes most obvious in the case of midwifery. It was rare to hear an Amish person differentiate between a formally educated, licensed chiropractor and a non-trained counterparts. Equally rare was a designation of difference between unlicensed physicians in Mexico using federally unapproved approaches and American medical doctors in those terms—as designations of the state. But due to the recent history of legal action against unrestricted midwives in the Lancaster area, many Amish mentioned those midwives as free agents unrestricted by state interference. Unrestricted midwives work on the borders of or outside the cultural world of biomedical training and practice. Here, the power of the state system becomes clearly aligned with the knowledge dualism—state power and biopower are both symbols and

manifestations of the knowledge of man. For the Amish, unrestricted midwives often tap into the knowledge of God by virtue of their being a more natural approach, by integrating elements of the familiar forms of homecare, and often by overtly religious claims. All unrestricted midwives I observed constantly referred to the power of God's hand in the birthing process during discussions with patients. During an interview, one garrisoned midwifery against medical models by invoking God's knowledge:

We don't believe that [cesarean is] the way that God intended for births to happen, and it really limits women's reproduction because of safety and health issues. Women die with surgery and cesarean's a major surgery.

She went on to proclaim a rate of only 0.1% unfavorable outcomes or neonatal death under her care—a low rate for which she must “give God the credit ... they're not my numbers alone.”

The history of legal action against unrestricted midwives also sways the way those midwives talk about their practices, their systems, and their patient populations. One of the most high-profile unrestricted midwives in the area is Diane Goslin. Goslin is a CPM; her training and education are not recognized or regulated in Pennsylvania and charges have been brought against her three times between 1996-2008. More recently, a grand jury was convened to review a number of her cases—one death and two newborns who required serious follow-up care in hospitals. Although the grand jury did not see criminal intent on Goslin's part, they did make firm recommendations to the Pennsylvania legislature that they should either “abolish unlicensed midwifery or ‘provide meaningful regulation of it’.” Their suggested regulations addressed much of the grey area in unrestricted midwifery: penalties for operating unlicensed birthing centers, penalties for falsifying birth documents, and requirements to inform women of their medical alternatives. Evidence had been presented that Goslin violated all three of these areas (Miller 2013).

Patients have brought none of the cases against Diane Goslin. The Amish, like most Anabaptist groups, will not utilize the legal system to seek retribution or bring suit against their fellow man. Men should not judge other men; the legal system, once again, is a manifestation of the knowledge of man. Health practitioners of all stripes are well aware that they have no fear of medical malpractice or wrongful death suits brought against them.

... a lot of the nurse midwives have referred their twins, their breeches, their VBACS, because those are political things that they could lose their license over. And since I haven't got one I don't have the fear of malpractice that I'm sure a lot of doctors do in terms of if they could have done an ultrasound and ruled out a problem or if they could have done a c-section, you know, and saved a baby possibly. I'm sure they live under a lot more fear of suit than I do ... I try and do the right thing because it's the right thing to do. Integrity's pretty important to me. But it's gotten me in trouble ... (unrestricted midwife in Lancaster County)

Despite the picture painted by many midwives in the area, Lancaster Amish do have babies and some other ob-gyn care at hospitals. Often assumed to utilize homebirth exclusively, one study estimates that close to half of the primipara Amish births in the Lancaster area now happen in a hospital setting; it remains likely that this number decreases significantly with subsequent births. To compare, 98.5% of births in the general population around central Pennsylvania occur in a hospital but only 46.3% of Amish primipara births (Miller et al. 2007:169). Despite their continued high rates of birth center and homebirths, obstetrics is clearly one of the areas where some Amish are utilizing biomedical services on a regular basis. This provides a fitting segue to the local, biomedical strand of the pluralistic system.

Biomedicine

The use of biomedicine among the Lancaster Amish does fluctuate—as suggested above; there are certainly families that will head to a physician or the emergency room more quickly than others. Likewise, there are physicians' offices and hospital services that are more likely to

see Amish clientele than others. Many decisions play out through the threads in the decision-making matrix discussed above and additional examples of those will be discussed in the chapters to come. Biomedicine, despite its typical position of authority in non-Amish western societies, does not enjoy that same position or symbolic social capital in the field of pluralistic medicine engaged by the Lancaster settlement. The field of plural medicine in Lancaster, however, does not result from a *challenge* to biomedical dominance in English cultural worlds; that dominance is simply not a given or recognized category. Instead, their overt neutralization of imposing outside hierarchies via mutual separation results in this pick-and-choose system where the power rests in the hands of the Amish as they choose which modalities properly address their bodily economies. As a general guideline, biomedical interventions are most typically used for intense trauma, genetic disorders, some ob-gyn care, and long-term illnesses with high rates of morbidity. Rarely sought for preventive care, seeing a doctor may be a second, third, or even fourth line of defense against a condition that has lingered or worsened.

Medical anthropologists have framed biomedicine as an ethnomedicine and cultural product for decades¹³⁸. I chose the term biomedicine in the tradition outlined by Hahn and Kleinman; biomedicine should be understood as a form of medicine with a primary focus on human pathophysiology, founded and still dominant in Euro-American societies (1983:306).

Hahn and Kleinman characterize the nature of biomedical standing among its adherents:

... participants of this ethnomedicine emphatically distinguish their medicine from other aspects and institutions of their society. Other than its science and its technology, Biomedicine is held to be clearly separate from religion, politics, economics, the arts (with token exception), aesthetics and morality. ... The central concern of Biomedicine is not general well-being, nor individual persons, nor simply their bodies, but their bodies in disease (312).

¹³⁸ Lock and Nguyen (2010) provide an excellent and current overview of these concepts. They look specifically at cultures of biomedicine through three themes: understanding the biomedical assumption that the human body is essentially uniform, their concept of “biosocial differentiation” where biological and social lives are mutually constitutive (1), and the importance of ethnography for interpreting biomedicine.

This indeed encompasses the broad strokes made by adjectives such as Western, allopathic, empirical, in-vivo. Contemporary biomedicine conceptualizes the body as a physical machine, reducible to its component parts, autonomous from the next body over. Indeed, biomedicine carries with it parallels between an assumed autonomy of nature in science and an assumed autonomous individual in the Western conception of personhood and society (Lock and Gordon 1988:11). Hostetler boils down a general definition of Amish health and illness as determined by one's ability to perform labor, and illness is determined by one's inability to perform that same labor (Hostetler 1980). The health economy rings crystal clear here when conceptualizing the health of an individual via an ability to perform labor roles. The Amish use biomedicine to treat trauma, debilitating illness, and more recently, certain genetic disorders. These fall decidedly into an illness category interfering with the ability to work¹³⁹. Paul Lehman recalled a time when he suffered an open fracture of his ulna.

Over in Lancaster General I got the bone set up by a hospital doctor. Metal—what are they—pinning? Pins? And stitches. I thought I'd go there due to it being through the skin, it figured there would need stitches for it. That doctor I'd never known before but if it was shorter to heal, well, that puts me out on the [construction] worksite quicker. I can't be around the house too long, I said! I'll go and see what I can do with one arm, I said!

One way to read this: biomedicine can be rationalized to provide appropriate care because of its ability to quickly return the body to laboring conditions (not due to its attention to specific symptoms or treatments). The biomedical construction of the body as an autonomous physical machine, reducible to its component parts, presents an apparent contradiction with Amish mutual separation. This impacts how the *Gmay* negotiates the use of biomedical intervention, how it understands the appropriateness of care, and how it navigates the inherent struggle between the

¹³⁹ In the case of genetic disorders, particularly among the pediatric patients seen at the Clinic for special children, this dynamic includes the future potentialities of becoming a working member of the Amish collective.

knowledges of God and man. Biomedicine generates one of the most concentrated arenas for the bodily knowledge dualism.

In Bourdieu's conceptualization of forms of capital, those in medical professions are in positions of power by virtue of their compounded investment of education yielding income. This position accounts for their ability to both create and conform to establishment norms (Bourdieu 1977:171). So, are the Amish an example of "the kind of society where we should expect to find the demand for spiritualized medicine", given Bourdieu's social epidemiology of capital (Douglas 2002:29)? It does indeed draw a parallel to Douglas's discussion of Indian ritual purity in that Amish communities are also inimical to domination, hostile to western science, and explicitly egalitarian. And it similarly places the simultaneous possibilities on a health practitioner of drawing authority from science and the society that produced that science (to the Amish—the knowledge of man) and of drawing authority from mysterious and cosmic sources (to the Amish—the knowledge of God). The positionality of biomedical knowledge in the English world as described by Bourdieu's system is inverted in the Amish one: due to the symbolic capital from compounded years of education, training and scientific-intellectual authority, biomedical physicians are understood as the paragons of an educational and economic system that devalues spiritual knowledge and suffers from its distance from God's knowledge.

Doctors are the high-holy priests in the idol-worship of human knowledge. While many Amish certainly have more nuanced descriptions of physicians they know or work with personally, the category of biomedical physician invariably gets described negatively. All of these descriptors drawn from interview data were used to describe doctors and hospital specialists: greedy, selfish, self-centered, self-praising, boasting wealth, taking advantage of others, benefiting from the sickness of people, ungodly. These attributes were noted as reasons

for drawing away from biomedical care, and many also expressed pity for physicians living lives “so out of touch with God’s message.”

Hostetler’s generalization about health and labor is a decent one; it gets at the heart of a community that values work and group-defined roles that help perform the laminated collective identity of the group and hold it together. Moreover, my generalization about science as antithetical to faith provides a decent proxy for Amish thought as well. Starting with these as background, it is important to now peer into more specific contexts of biomedical care in the Lancaster area and begin uncovering the continued complexities inherent in healthcare decisions among the Amish.

Medical anthropology has a pattern of uncovering and investigating dysfunctional relationships in the clinical context. Biomedical models arrive via global health vehicles to communities around the world. Immigrants in the US, non-English speakers, or those with severe socio-economic disadvantage arrive in the clinical setting with a gulf between them and their practitioners—a gulf filled with missteps, misunderstandings, missed opportunities. Asylum seekers and foreign-born workers attempt to navigate these often-insensitive health bureaucracies and clinical hurdles. Medical anthropology is full of these kinds of chronicles, and many of them highlight dysfunction that occurs when biomedicine and patients familiar with other ethnomedical systems interact. This would not be a terribly difficult story to tell with the Amish. An Amish woman working as a receptionist in a local doctor’s office made the point:

Everyone has a story, themselves, their cousin, who ever! Our people will tell you something about how they got the advantage taken from hospitals or doctors. Either the bill or they way they’re treated. Putting them on some drug medicines for something they don’t need. It’s a shame! You know, my cholesterol was 140 points on the scale and this doctor, she put me on the medication for your cholesterol. I thought I’d take it and after I had, well he [employer] asked me the level. 140, I said and he was ‘Woah!’—I should not be taking that for any such number! The money was spent on the medicines and the visit. Supposed to have blood tests. Our people, we pay [with cash]. So why did that

woman doctor say those things? Greedy for the money, I guess. Or just trusting too much in something she's got from a book. It's not right, I am telling you. And that's no big story—I threw those pills out. But there are big stories. Kids in hospitals. People getting accused of things. It's just not right to do that to our people.

Sketching out a case study of clinical dysfunction as the Amish negotiate biomedical strands of their own plural health field would easily echo her anecdote. I heard stories of Amish mothers receiving medical instructions for their children that they found impossible to interpret or understand; stories of families being made to feel blameworthy for taking an elder out of the hospital to die of cancer at home; stories of extreme confusion when one hospital doctor gives a set of instructions and after the shift change another doctor rewrites the script completely; and many tales where Amish families are acutely aware of being talked down to because the doctors “seem sure we are all slow. We're Amish, not stupid.”¹⁴⁰

The distinctive case here provides a more rich and fascinating study. And, in its inversion of the trope, it still incorporates many elements of how the Amish interaction with biomedicine has potential for going awry. If biomedicine may be prey to the generalizations suggested above, why is it used at all and when it is used most successfully? This is where the Clinic for Special Children enters the picture; CSC and its practitioners hold an interesting position in the plural health field. In many English families, having a child diagnosed with a genetic disorder automatically, by social expectation and/or moral force, requires treatment in the biomedical realm. For the Amish, this link is not imperative; they maintain a position of power and the clinic is thereby subordinated through Amish decision-making about medical treatment at CSC.

Despite that reversal of symbolic capital for biomedicine, the clinic also holds a position of

¹⁴⁰ This short quote was taken from a particularly indignant teenager, complete with full eye-roll. She was describing a visit to Lancaster general when an emergency room doctor started talking to her father in slow, loud, choppy words. “Like a toddler,” she noted, “he was talking to my dad, this older Amish man twice the doctor's size like he was a toddler or could not hear or something. He turned to me and my mom and made a joke that maybe English was not the doctor's language. But he said the joke in *Deitsch*, so the doctor didn't laugh.”

power in their vision of something that remains otherwise invisible to the Amish. The lack of scientific education about body systems, germs, and genes in Amish education creates differences in knowledge about genetic disorders for the Amish family and the non-Amish practitioner. Genetic disorders clearly fall into the Amish categories of illness that remove an individual's ability to labor and impact the entire family's ability to labor. Etiologies and treatment strategies, however, remain unclear in their link to health and illness. A baby may look healthy and demonstrate all the signs of becoming a typical child and adult. When screening from CSC comes back positive for a genetic disorder, the clinic and its staff are put in a position of authority due to their knowledge of something that might not otherwise be visible (yet) to the family or community. But the family's acquiescing to biomedical intervention is rarely guaranteed. This, of course, affects the clinic's operations and dealings with the Amish community. Just as the Amish are well aware of their power in the decision to use the clinic, the clinic practitioners are well aware that they are being negotiated with and negotiated by the Plain communities they serve. Here we see real Amish bodily economy accommodated on the field of medical pluralism¹⁴¹.

A Church with Cancer and Amish Aid

One particularly blustery afternoon, I headed out to pick up Sadie Graber's kids from their one-room schoolhouse. The winter had been cold—bitterly cold, even for Pennsylvania—temperatures only crept above freezing for a few days of January and little of February. The Graber kids' schoolhouse, of course, has no parking lot to speak of and the shoulders were packed with plowed snow. With some embarrassment, I crept slowly alongside an ongoing ball

¹⁴¹ The full exploration of CSC as a case study will continue in chapters 4 and 5.

game in the schoolyard to get close enough for my charges to know I was there. After piling backpacks, lunch pails, and black-wool snow bonnets in the back of the Subaru, Matthew—the oldest of the school-age kids in the family—got in the front seat and rattled off directions to our destination in *Deitsch*. His sisters started giggling as they fawned over the toddler in her car seat. Turning bright red, Matthew repeated the first step of the directions in English, although these had been the only bit I had actually understood the first time around. Arriving fifteen minutes later at a small Amish grocery store, all of the parking spaces for cars were open and the storefront looked all but totally empty. As we rounded the building on foot, life sprung up with the stomp and steamy breath of tethered horses. Teams were lined up en-masse down the side and I followed the kids racing from the cold to the loading entrance—half wondering which older child had released the toddler from her car-seat and whisked her away.

Things were abuzz in the warehouse. Straw-hatted men scooted back and forth with large bulk boxes of things like deli meats, tomatoes, sub rolls, little packets of mayonnaise, and women with children gathered around long tables set up in assembly line fashion putting together row after row of cold-cut submarine sandwiches. There were about sixty people working, and the din of chatty Amish women reverberated loudly from the high warehouse ceilings to the point that I had to raise my voice to talk to the person next to me. All the littlest kids were put to work flattening boxes; someone would cut the tape off, throw the box to the ground, and a gaggle of girls and boys would joyfully jump all over the new cardboard target at their feet. I quietly hopped in the line-up putting one handful of shredded lettuce on every sub that came down a line. The compound noise made it hard to translate conversations on the fly, much less reply with any aplomb. Stories and local goings-on swirled around as handful after handful of lettuce was placed upon slice after slice of deli meat. A few hours later, the last of 5,000 sub lunches came

off the line. These were assembled with materials bought at wholesale for about \$1.10 each, and already sold as preorders to area businesses, Amish schools, and other offices at \$4.00 each—a profit of over \$14,000.

The Amish carry no health insurance and they almost never participate in federal or state aid programs like Medicaid or social security¹⁴². An important part of their church lifeway, however, is practicing constant mutual aid within the church community. This might mean participating in something on a grand scale like a barn-raising. Or it might mean smaller moments like a parent's never looking far for eyes to watch a child. Like the toddler being whisked from her car seat, older children or those with free hands often appear when a mom needs to do a little other work. This is church; and church is life. As mentioned earlier, healthcare has become an arena where this constant mutual aid gets formalized through organized Amish Aid programs.

Just a few weeks later, I was sitting across the kitchen table from Barbara Frey when she mentioned that their district had just completed a similar fundraising event via sub-sandwich sales. Barbara's neighbor was in charge of planning a spring mud sale with chicken dinner to continue raising funds. It turns out, Simon Shenk lives in Barbara's district; he has a pregnant wife and works in an Amish furniture workshop. Simon, age 42, also has non-Hodgkin lymphoma. He has bills from months in the hospital at Hershey, lengthy unsuccessful cancer treatments, multiple failed attempts at alternative care, one trip to Mexico, and upcoming costs of in-home hospice. Simon's bills dwarf his yearly income five-fold; so his district has drawn together to cut onions, slice tomatoes, and flatten boxes to begin repaying his bills for him. And a similar \$14,000 profit won't be the full extent of money his *Gmay* will raise for Simon's needs,

¹⁴² Note that the Amish are exempt from participating in social security. For a full account of the legal battle to obtain this exemption and the supreme court decision of *United States vs. Lee*, see (Ferrara 2003).

just as they will do for any of the other dire cases that their district faces in the future.

Barbara and the kids chatted respectfully about Simon's family while peeling potatoes that Barbara's oldest daughter, Sarah, had hauled in from a root cellar built into a berm by the back of the house. It turns out that her son, Joshua, had taken to dropping by the Shenk place to pitch in from time to time—"help keep their place neat, help keep it as it should be and all," Barbara chirped. I asked Barbara about Simon's situation and the Amish Aid program in her district; her first response came in German: "*Alle aber, die gläubig geworden waren, waren beieinander und hatten alle Dinge gemeinsam. Sie verkauften Güter und Habe und teilten sie aus unter alle, je nachdem es einer nötig hatte*"¹⁴³. All of the believers were together; they had all things in common together. They sold off their belongings and goods, and gave them away to all according to whichever one had need. "Money you have—that is of this life. And we should give to the ones that have needs." While the Amish do not live fully integrated commune-style lives like their Anabaptist cousins the Hutterites, they do live in closely circumscribed small communities that practice this kind of constant mutual aid as any has need. A core value in Amish spirituality is that of the bounded community, the *Gmay* held together by social practices ranging from plain dress to common language. It is the *Gmay* that forms the locus of Amish communities of practice. And it is the *Gmay*—not personal need—that motivates many decisions.

That evening, after dinner, I could not turn down the offer for hot tea before leaving, despite the late hour and the icy paths. After getting ready for bed, most of the kids had gathered back in the living room when the fifteen-year-old, Sarah, started to read rhythmically to all of the

¹⁴³ This scripture reference in German was likely memorized from the Luther Bible translation in high German. The Luther Bible remains the standard text among Old Order districts in the Lancaster area. These lines come from Acts 2:42, translated here by the author. Acts 2 is preached on regularly in the Amish church lectionary, usually around the time of Pentecost. A formal English translation of Acts interprets the lines as follows: *All who believed were together and had all things in common; they would sell their possessions and goods and distribute the proceeds to all, as any had need* (NSRV).

younger kids snuggled under blankets on the couches. We took our tea, another LED lantern, and joined them. Many evenings at the Frey's ended with bible stories or other devotional bedtime tales. But tonight, Sarah pulled down an old and slightly tattered copy of the second book of *Martyrs' Mirror*—a text that, among other things, outlines the crimes and deaths of over 800 Anabaptist martyrs (Bracht 1685). That night's bedtime story was about Anneken Van Den Hove. She was turned in to the authorities by a pastor on charges of being an Anabaptist, examined, tormented, threatened, and then imprisoned for over two years. In 1597 she was escorted just outside of Brussels, asked one last time to renounce her Anabaptist faith and upon her refusal was publically buried alive by a justice of the court and a group of holy Jesuits. Joshua, age 10, grabbed at the book and the kids gathered to see the etching of Anneken's death¹⁴⁴. In the print, one man shovels while caped officials speak accusingly to Anneken with pointed fingers. Her body is buried and only her head is still above the spoil line as a shovel full of earth is being tossed her way with crowds watching and the spired city of Brussels looming the background. This bedtime story was no *Good Night Moon*.

A short discussion sparked up about suffering and the kids seemed surprisingly comfortable and familiar with Anneken's kind of sacrifice. Barbie—an astute twelve year old—made the theoretical leap between Anneken and Simon, complaining that his suffering was different because he did not choose cancer as one chooses to get baptized into a church. A deeply insightful comment about the human condition of moral choice-making from a twelve year old, indeed, but it was Barbara's response that stuck with me. "Simon's suffering," she noted to her young daughter, "teaches us all how to love one another righteously." Barbara lauded Simon for trusting in God and knowing that human-led healing is flawed, human-led anything is flawed.

¹⁴⁴ The engraver and early Anabaptist, Jan Luiken, created over 100 copper etchings for print in the second edition of Bracht's *Martyr's Mirror*. Many of these are scenes of persecution, torture, and brutal executions.

And it was not just Simon that was sick, she continued, it was the whole of their district.

Amish spirituality, with its emphasis on the binding of community, sees God sometimes using great suffering to gather sheep toward the shepherd. Indeed, Amish spirituality dictates that a life dedicated to Christ forms a gate; a fence around this community electrified by the *Ordnung* allows for the flock's safety under God's watchful eye to prevent the wandering and protect the suffering sheep¹⁴⁵. "If we can't come together for that one that has sickness," Barbara told me, "we aren't much of a flock if we can't do that." Operating a community that responds to members as each has need results in the interpretation of suffering, straying, or threats, as instances that call for the group to turn in on itself and play out social practices that enforce loving one's fellow group-member in a spirit of righteousness. All at once, the group recognizes the nature of the individual and folds those concerns into the identity of the collective.

A few Sundays after that night at the Frey's home, I attended church in a different district just up the road. Per usual, there were two long stretches of speech that Sunday morning, each preached by a different man. The lessons for the week came from scriptures about the vine and the branches¹⁴⁶ and the preaching flowed extemporaneously with no notes or manuscripts. At some point after talking about "*Euer Herz erschrecke nicht und fürchte sich nicht*"—no heart be troubled and neither let them be afraid¹⁴⁷—one of the preachers veered off on a reference to the 23rd Psalm. After missing some bits and pieces due to my slow uptake of preaching, I spent much of the community lunchtime chatting about that tangent with the Amish friend that had brought

¹⁴⁵ This theme arose frequently when I talked to adults about being part of a community. The idea of Jesus, or spirituality in general, acting as not only a shepherd of the flock but the gate that closes around the community comes from John 10 (NSRV):
So again Jesus said to them, Very truly, I tell you, I am the gate for the sheep. All who came before me are thieves and bandits; but the sheep did not listen to them. I am the gate. Whoever enters by me will be saved, and will come in and go out and find pasture.

¹⁴⁶ Book of John, chapters 14 and 15

¹⁴⁷ John 14:27—"Do not let your hearts be troubled, and do not let them be afraid" (NSRV).

me that morning. Expectations may assume the gist to be along the lines of fear and protection as we walk through the dark valleys; but this sermon did not emphasize Jesus beside the wanderer, a soft luminosity casting a protective glow over each treacherous step the lonely sheep takes or every temptation faced in life. The 23rd Psalm is often preached in Protestant circles as a funerary text. Even in dark times, God will walk beside you as you encounter challenges on your personal and spiritual journey. Instead, this Amishman preached 23rd Psalm as verification: because their community continues to be bound very tightly by the gates of Jesus' teachings, *mir wird nichts mangeln*—I shall not want.

There are clear differences amongst Amish Lancaster County, some of which have already been explained or alluded to. Amish in some parts of the county, namely those nearest the thriving tourist trade (which mostly coincides with the oldest Amish settlement areas in the county) can amass considerable wealth while those in other areas are significantly less financially secure. Leaving Lancaster County and heading out into more rural Pennsylvania and the western part of the state, Amish have significantly fewer financial resources. There is a real disparity, even within districts at times between families that have more of a financial buffer and those that do not. Why don't the Amish simply pool their money if they aim to meld autonomy so fully?

This is a fascinating difference between the Amish and a more communal-style group like the Hutterites. The cultural world of the Amish is made up of these communities of practice striving to minimize self-will and individuality for the good of the laminated whole. And that effort revolves around faith in God—a faith so directed by the knowledge of God that there should be no structure, no polity, no state between man and God. In true Anabaptist form, they are the full antithesis produced during the reformation, the ultimate acephalous church. The

Amish don't build church buildings partially because they avoid creating a centralized body—even one that is fully *Amish*. Amishness can never be an ontological state by virtue of its place or structure; it is always in the making by virtue of its practice.

This speaks to the idea I call quiet equity. Amish use cultural artifacts, materiality, and economies of health to smooth over individual differences but financial and other disparities remain. These differences are made evident from time to time but are generally held at bay in favor of a silence about the financial states of others within the *Gmay*. In most cases, the value of a family's holdings is kept intensely private; parity arises out of shared silence—the quiet equity. At the Amish and America Conference held during the summer of 2013, Richie Lauer spoke about Amish charitable giving. Lauer is the foundation officer for the Anabaptist Foundation, a division of Anabaptist Financial that focuses on donations from and to conservative Anabaptist and Plain communities. He pointed out that sometimes he may be the only one who can pick a wealthy Amish millionaire out of a crowd because he may be the only one with access to information about that man's financial assets. Amish want to be offered the opportunity to serve, he noted, but they don't want to be known or given recognition. His foundation offers the cover-up, the middle man, for wealthy Amish to funnel money into non-profits or other charity. They hardly ever carry much debt, they have no need for capital campaigns, and much of their donated money goes straight into healthcare outlets.

Requirements will be fulfilled, as any have needs. In other words, the preacher was not presenting this familiar Psalm as a tale of journeying alone with the shepherd through rocky trials and shadowy tribulations. As in many other areas of Amish life, the “me” in the 23rd Psalm became corporate. It is the whole flock that wanders through green pastures together with tables laid out before them and cups running over because they are bound together inside the gates of

Jesus' teachings. Untouchable by virtue of that rod and staff, the flock can simply rest, quenched next to still waters because the shepherd frees them from *want of worldliness*. This preacher's intention, of course, was not to suggest that their lives are easy or that they do not face spiritual and personal difficulty. Simon's family can tell us a great deal about personal struggle. So can each of the Amish families at the Clinic for Special Children, as they care for kids with genetic disorders and sometimes-profound disabilities. But constant mutual aid as any have need reinforces suffering as an opportunity to learn to love. Not sheep in a flock, but a flock of sheep.

Conclusion

The Amish offer us an opportunity to continue removing classifications of societies as though they are the kind of "natural", tightly circumscribed cultural groups that anthropology helped colonial officials imagine in their control over the marginalized "other". Instead, illness and the health encounter in Amish communities are illustrative of pluralistic systems that require actors to participate in negotiations across difference both internal and external to their group identity and always mediated through cultural artifacts—in many cases, medical technologies of one kind or another. Pluralistic medical practices allow communities to deploy culturally-constructed strategies and evaluative criteria (Kleinman 1978:87), and anthropology's work with the health encounter offers important insights into what can happen in these settings.

My original formulation of this research had me putting equal weight on and investigating fully each of the strands outlined above. Even now, these seem to me to be merely viewed with a shallow glance—each deserves a full unpacking and detailed case study. But that would have provided the data for five dissertations. So, I push ahead by narrowing my ethnographic gaze into the plural system, into the biomedical strand, and I land resolutely in one

of the more interesting clinics serving Plain populations today: The Clinic for Special Children in Strasburg, Pennsylvania.

Decisions made in Lancaster Amish church districts regarding the use of genetic technologies are delineated by and heavily influenced by the cultural practice and group identity introduced above. New healthcare options have been introduced into a community in need around Lancaster; sets of people have been abruptly brought into relationships with new knowledge and technologies. Frequently, these technologies and scientific efforts presume and/or create expectations of persons as self-conscious, autonomous subjects (Adams and Pigg 2005). Consistent with their training, biomedical practitioners often deal with individual patients as discrete units. This creates an immediate disconnect as the church districts in Lancaster, as well as in Amish settlements all over North America, foster cultural understandings that expunge individual expression and place a primacy on the group. The clinicians at CSC have attempted to make adjustments to this model in order to serve their patient population. This dynamic, combined with the community-wide standards for the use of technology and the fact that Amish communities were not geographically isolated during the “rise” of modern understandings of the body are all unique historical and cultural circumstances. At the center of these circumstances are the interactions between patient families and practitioners negotiating across cultural difference. The negotiations that occur between local illness careers (Csordas 1988, Fabrega and Manning 1972, Pescosolido 1992) and interactions with types of medical treatments are important factors in shifting socially constructed definitions of disease (Mishler 1981, Waxler 1981, Lindenbaum and Lock 1993, Mattingly and Garro 2000).

Biomedical culture itself can be understood as a moving target, particularly in regard to its pace of technological innovation. Technoscientific change constantly reconstructs the many

sites of medical “knowledge production, distribution, and information management” (Clarke, et al. 2003:162). Recognizing that social features of illness experiences contribute to the formation of personal identities remains important (Fabrega and Manning 1972); this project adds to that dynamic by focusing on a social world where the group’s identity reigns over any individual concerns, preferences, and privileges. As a twist in the search for implications of bodily practice on group identity (Farquar and Lock 2007), these communities inevitably invoke the collective as a primary consideration and group identity inevitably impacts bodily practice. This issue of autonomy and its impact on bodily practice will be addressed in chapter six. But first, I must point my attention to the unavoidable Amish individuals. More specifically, I will consider the characteristic that is at once their most individual attribute and at the same time the thing that ties generations together in their cultural world—Amish DNA.

Chapter 4: A Medical Home for Genetic Issues among the Lancaster Amish

Introduction and Two Strands

After describing the plural health practices of the Amish in Lancaster County, I now turn my focus toward the biomedical strand of the plural system and the high-tech translational genetics available to Amish people in this area. This brings us up to the second set of the driving questions introduced in Chapter 1. Taking biomedical genetic medicine as a case study, what can we learn about general Amish practices for negotiating technologies and the results of such negotiations for the stability of Amish cultural constructions? In other words, how are districts that use the clinic adapting and elaborating genetic medicine and how is the process of negotiation reshaping Amish understandings and practices?

This section begins to address *how local Amish cultural identities and standards for technology are being modified in light of their desires to access the benefits of modern genetic medicine* by looking at genetic medicine's historical arc in the Lancaster community. Addressing this driving question through the case of CSC requires me to provide background on the ways local Amish negotiate, accept, and reject the highly technological, individualized medical models in the setting of translational genetics discussed in the next chapter. To begin, I review the historical connections between the Lancaster Amish and the field of medical genetics. Then, I provide a short history of the Clinic for Special Children (CSC) and early understandings of glutaric aciduria type 1 (GA1). Such micro-histories are common to extended case-analysis as

they permit emphasis on the emergent properties of the social (Handelman 2006:108). Here “the social” should be thought of as the cultural worlds of the Lancaster Amish—that laminated collective that form in communities of practice around Amish mutual separation.

Amish families and the *Gmay* began coming into contact with genetics in the 1960s. Particular families were required, in some ways, to move to the edges of their familiar cultural world and navigate the frayed edges of the laminated collective. By following traces of the social “as associations through many non-social entities,” my historical account will hopefully return to a “shared definition of a common world” (Latour 2005:247). These non-human entities are many: genes, shared blood, common ancestors, soundwaves, hospitals, wheelchairs, old cars, door-to-door salesmen, urine, organic acids, striatal lesions, timber frames, rocky outcroppings in an Amish cornfield, the Wall Street Journal, second mortgages, mass spectrometry, newborn screening, and so on. I pick up the story years before the Clinic for Special Children was established to wind our way there along one area of Amish engagement with biomedicine.

In Chapter 1, I pointed out that geographical, economical, and local contexts greatly shape Amish practice. The Amish “church,” is held together by a set of common histories, ideals, and practices—but each *Gmay* and each regional area of localized communities of practice are always in the process of developing and defending their cultural worlds. The metaphor of the Amish as a quilt patched together from diverse pieces but stitched by a unifying thread into an interconnected whole remains apt. From the outside, Amish society often appears to be a well-crafted whole, projecting an image of a plain, simple, ahistorical, and homogenous group. In reality, settlements and districts are stitched together as complementary yet distinct patches. Here, I extend this metaphor to suggest that the thread holding together a continental Amish patchwork is composed of two undulating threads.

The first thread forms from a shared belief in spiritual discipline where “faith should inform all aspects of life” (Meyers and Nolt 2005:39). It builds upon continuities with the past and upon the shared sensibilities (Hurst and McConnell 2010:24-25) cultivated in similar cultural worlds through interacting with the similar artifacts associated with those worlds. Each *Gmay* shares with the next through a network centered around the biblical Gospel and Apostolic texts, the Dordrecht Confession, the *Ausbund*¹⁴⁸, similar contents of each *Ordnung*, and forms of communication (real-time and textual). This is the first of the two undulating threads I propose, and it is the thread, typically emphasized by scholars, that stitches together that Amish patchwork. It tends to focus on the spirit—the social and transcendent nature—splitting it from the body—the physical and manifest nature. But Amish communities, despite their self-determination, are held together across the continent by strong threads from that second category. Intertwined with lived bodies in cultural practice, this other thread that joins the Amish together as a wider community—the common base pairs lighting up their DNA.

Founder effects and genetic drift

Picture a hypothetical island out in clear waters where the jungles grow thick with lush green foliage and animals of every type. On this island resides a species of tree frogs that come in a brilliant array of bright colors. Each frog is splotched with a single florescent color against a black background. One afternoon a great earthquake shatters the island and opens up a ravine to the west. Seawater gushes through and fills the newly formed feature. The one island has suddenly become two, with the western tip—about a quarter the size of the original—now

¹⁴⁸ *Ausbund* is a swiss-german hymnal still used by Amish districts across North America and Canada. It is one of the oldest hymn books in continuous use. See (Friedmann, Robert 1953. *Ausbund*. *Global Anabaptist Mennonite Encyclopedia Online*) for a short history and good bibliography of relevant academic work.

surrounded by sea on its own. As it turns out, there were only two colors of frogs that survived far on the western edge after the tsunami of water rushed through. Purple and red hop around abundantly, but there are no oranges, yellows, blues, greens, or any of the other shades on the new little island. And the gulf between the two is much too far for these freshwater frogs to swim. But the frogs don't think twice about their orange brothers and sisters back on the big island. They just do what frogs must—they make more frogs. In the next generation almost all of the frogs are purple and red, but a few yellows and greens pop up. Ten generations later, the majority of the frogs are purple or red; a minority is yellow or green. And so it goes for the little island frogs; some of the colors are lost to the population forever and others become exponentially most common.

The story of these colorful frogs illustrates a population bottleneck and genetic drift in action. Genetic drift comes about from random changes in a population and a bottleneck occurs when those random changes are magnified by population size—perhaps a group gets stranded by an earthquake or perhaps a subset sets sail for a new world far away from their genetic families. This, along with natural selection, is a primary force in the evolutionary process. There was no particular reason that the purple and red frogs survived the melee, but due to their random luck, they will pass down purple and red-producing genetic material in greater proportions compared to any generation that came before. Within their new population, the frequency of those red-causing and purple-causing alleles has suddenly skyrocketed. What's more, these frogs can illustrate a certain kind of bottleneck called the *founder effect*. When a new group of individuals separates from the larger population, they essentially “found” a new population that is limited to the genetic material at hand. If there is an allele missing in that population, like the one that causes orange coloring, that phenotype will be lost forever to any future offspring. Likewise, if

there is some deleterious genetic change among those founders, that change may become increasingly common as generations progress. If one of those little-island frogs carries a gene that inhibits the membrane production on the frog's exterior and thereby makes it more susceptible to the deadly red leg disease, that one frog is suddenly a much bigger player in a much smaller gene pool. His deleterious change will be passed on at a higher rate, relative to the population size, than it would have been back on the big island. Further, as new generations are born, random genetic events (ie. genetic drift) can have a major impact because the population is so small.

There are many examples in human populations of bottlenecks like the founder effect. Some are the result of pure geographical and genetic isolation, some the result of cultural endogamy. Many result from a combination of these features or other isolationist factors that place physical and imagined boundaries around who may reproduce with whom. The resulting populations, sometimes very large ones, propagate similar genetic material over many generations because they were founded by a small number of individuals. And the ensuing offspring are shaped both by the increased allele frequency due to bottlenecks and the intensified impact of random genetic drift.¹⁴⁹

New World Anabaptists are famous examples of founding populations. Like genetic drift anywhere, deleterious changes in Anabaptist genomes have and will increase or decrease randomly. But since these founding subpopulations are small, these kind of shifts can be profound; "some rare mutations become quite common, while others become extinct" (Strauss

¹⁴⁹ Many assume that deleterious conditions in founding populations are the result of inbreeding between close relatives, but this should be clarified. Inbreeding, as defined in genetics, occurs when a breeding pair has any significant degree of consanguinity. Inbreeding is not synonymous with close-relative (fourth degree or higher) mating. Inbreeding alone does not change allele frequencies but it does increase the probability that consanguineous individuals will reproduce. It does alter the genotype frequencies in the population (increasing the frequency of homozygotes and decreasing the frequency of heterozygotes). In other words, inbreeding exacerbates the effects of genetic drift. But this is different than assuming that populations operate under lax incest taboos or allow close cousin marriage. The Amish, in fact, do not condone the marriage of first cousins.

and Puffenberger 2009:516). As described in Chapter 2, early pockets of Amish immigrants dwindled somewhat in the colonial era. The eastern Pennsylvania Amish fit this pattern until the Lancaster settlement began to solidify in the early nineteenth century. Amish families lost members to other movements or faiths and genealogical records indicate that they gained very few outside converts in return. This resulted in a biologically insular, endogamous group.

Most importantly, because colonial Anabaptist groups were established by distinct individual founders and then developed into relatively closed populations, each subgroup became a genetic world into itself. In other words, the Lancaster Amish are an entirely different founding population than their geographical and ideological neighbors, the Old Order Mennonites. And Amish groups that came together subsequent to the Lancaster settlement also have their own distinct areas of homogeneity, like the Amish in the central “Big Valley” area of Pennsylvania (such as those in Mifflin and Juniata counties). Because of this divergent homogeneity within founding populations, an Old Order Amish person living in Lancaster County has less genetic similarity to an Old Order Mennonite from just up the road than he would to a non-Anabaptist from the general population living in downtown Lancaster. In other words, the intensified impact of genetic drift has rendered Amish and Mennonite populations, no matter their similar historical background and European roots, into largely isolated genetic products¹⁵⁰. Aside from sequence data and phenotypic outcomes, *isonymy*¹⁵¹ provides a striking proxy for how these populations have developed separately while constantly folding in on themselves.

¹⁵⁰ Strauss and Puffenberger (2009) provide detailed evidence illustrating these differences. For example, after determining allele fixation resulting from drift (118 SNPs are fixed among Mennonites, 204 among the Amish), they point out that comparison of allele frequency between three populations (Lancaster Amish, Lancaster Mennonites, European control set) illustrates that the Anabaptist subpopulations were more similar to the European than to one another. Further, of the 67 disorders they had delineated in the Plain population at that point, only five are found in both Amish and Mennonites and only two are the same at a molecular level. They note: “genetic differential diagnosis depends critically on population of origin” (518).

¹⁵¹ Isonymy is the practice of using surname frequency to determine or illustrate the degree of relationship in a population. It typically depends on patrilineal descent.

The Amish are known for their meticulous genealogical record keeping but scholars, the Amish, and medical scientists have often relied on slightly different sources. Historical accounts tend to draw heavily on the usual suspects: wills, property records, ship logs, and the occasional written family history. Within the community, *The Fisher Book*, other compiled lineage records, and oral history traditions are the primary sources. In the past, the medical genetics community tended to pull from the former category, but in the early 2000s, a team of scholars came together to tackle the task of creating a robust compendium of historical accounts, formal genealogies, family records, and other archives. The Anabaptist Genealogy Database (AGDB) combined three major source works (Agarwala et al. 2003). They began with *The Fisher Book*, but this biased the scope to the Fisher line alone. They next added data from a volume titled *Amish and Amish Mennonite Genealogies*. This data focused on individuals before 1870 and balanced the early population to include a better sample of bloodlines. Lastly, they incorporated an existing computer database maintained by a private individual and genealogist, Mr. James Hostetler. The ongoing Hostetler database compiles information from a myriad of sources including church directories, personal correspondences, and other genealogy texts (Agarwala et al. 2001). As a result, the fourth iteration of AGDB now stands as a robust database including 417,789 individuals and 102,341 marriages. Using query software, AGDB can be probed to solve complex pedigree questions and is used primarily by medical geneticists working with Plain populations (Lee et al. 2010).

A published series of queries investigating the exact nature of Lancaster's Old Order Amish founding population created a 14-generation pedigree. Their analysis showed that just 128 individual founders accounted for over 95% of the genetic contributions among all of the Old Order currently living in the Lancaster settlement—what geneticists deem a “truly closed

population” (Lee et al. 2010:9). This number of founders is slightly higher than previously reported in the medical literature but is likely more accurate due to the widened base of primary source material. And these kind of closed, founding populations are valuable in genetic studies because they make proximity in sequencing data highly useful for pinpointing the location of deleterious variants. Due to common ancestry, disease alleles may be easier to find due to the relative physical location of traceable marker alleles and deleterious alleles (linkage disequilibrium) or they may be easier to find due to identifiable patterns passed down from the founders (haplotype analysis) (Martin and Speer 2003:38). The lack of new genetic material, equitable social-economic standards, and their detailed genealogies make the Old Order Amish well-suited for identifying some rare deleterious alleles (Lee et al. 2010:9).

Victor McKusick and the Lancaster Amish as Subjects for Genetic Studies

Due to this suitability for genetic study, researchers have worked in varying capacities with the Amish population across North America for the last 50 years. One of the first and most well known of these scientists was Dr. Victor McKusick. Often referred to as the father of medical genetics, McKusick’s career pushed human genetics toward applicability in clinical medicine. In an edited volume describing his life and impact on medical genetics, the subheadings in the introductory chapter offer a taste of the immense impact McKusick had on the field. Just to name a few: [developing a] division of medical genetics, misconceptions in human genetics, genetic nosology, gene mapping, the human genome project, inbreeding among the Amish, genomics, MIM and OMIM. McKusick wrote or co-authored an impressive 772 publications from 1949-2008 (Dronamraju 2012). In 1962, McKusick was on the faculty committee advising John’s Hopkins Press when they received the manuscript of *Amish Society*

from John Hostetler.¹⁵² For the book, Hostetler had examined health related issues in twenty-six issues of *The Budget*, interviewed almost fifty physicians who had worked with Amish from Pennsylvania to Iowa, and found that “the Amish, when they were in need of health care, favored both folk and Western medicine, seeing no contradiction between them” (Lindee 2005:67).

At the time that Hostetler’s manuscript arrived, McKusick had already begun studies in families to determine genetic etiologies for autosomal dominant traits and x-linked traits. In Hostetler’s work he recognized a set of societal practices that were ideal for studying autosomal recessive disorders—and they were only a few hours away from Baltimore. McKusick and Hostetler began a collaboration that lasted decades (Francomano 2012:119) and McKusick often used Hostetler, who was ex-Amish, as his cultural broker. The two coauthored an article in 1964 titled “Genetic Studies of the Amish: Background and Potentialities.” In it, the authors outlined fifteen distinct characteristics of Amish social life, biological makeup, and cultural practice that make them uniquely “useful for genetic studies” (1964:211-214). Here, each bullet in the list has been shortened for brevity:

- 1) The Old Order Amish constitute a defined population, in fact a self-defined population. There can be no question of who is presently Amish, although there may be question of who may have Amish ancestry.
- 2) It is a closed population. The Amish do not proselytize and marrying outside the faith is forbidden. Although some leave the group, very few “new” persons enter it.
- 3) The origins of the populations are western European and are rather well known.
- 4) Genealogic records are extensive. Most Amish can trace their complete ancestry back to the immigrants from Europe. The interest of many simple peoples in genealogy is a matter of note.
- 5) The standard of living is high. The genetic factors in morbidity and mortality are less likely to be swamped by non-genetic ones, such as malnutrition and infection.
- 6) The standards of medical care are relatively high. Although the Amish tend to be attracted to fringe and unorthodox practitioners, they do make use of the diagnostic and therapeutic facilities in neighboring medical centers.

¹⁵² Originally published in 1963, the updated edition of Hostetler’s seminal work is used throughout this dissertation (1993).

- 7) A great interest in illness is evident. For example, *The Budget*, a weekly newspaper which caters particularly to the Amish, frequently carried lengthy and detailed accounts of illness, provided by its Amish correspondents all over the country.
- 8) Because of the strict endogamy, the relatively small number of immigrant ancestors, and the limited size of the subgroups, a relatively high mean coefficient of consanguinity must exist.
- 9) The illegitimacy rate is probably low. The regulations of the church appear to prevent illegitimacy quite effectively.
- 10) The Amish are clannish and usually have information on other Amish, especially as concerns some illness or defect which is present in a close relative.
- 11) Socio-economic and occupational circumstances are notably uniform. All are rural-living, most are farmers, and poverty is non-existent.
- 12) Because of their dedication to horse-and-buggy transportation and to an agrarian life, the Amish are more immobile than most other people in this country.
- 13) Large families, averaging seven to nine, have long been the rule among the Amish. Whereas non-Amish parents may stop having children after the birth of one or more defective children, Amish parents seem not to be influenced by this factor.
- 14) Defective individuals, including the mentally retarded, are usually not institutionalized but rather are kept at home. Thus, such cases are more readily identified and studied in relation to the rest of the family.
- 15) The existence of several separate Amish isolates, particularly those of Lancaster County, PA, and Holmes County, Ohio, makes comparisons possible.

Most of the items on this serve to illustrate extreme endogamy bolstered by space, place, and practice. The list further supports a kinship system that includes fidelity, fecundity, and patrilocality. All of these factors, plus the fact that the Amish “have their origins from a relatively small number of immigrant ancestors” (McKusick et al. 1964:211) indicate the high probability of discovering new information about disease states with recessive inheritance patterns. The list above has remained notably stable for the last four decades; many of these generalized facts remain the same excepting number five and number eleven. For example, while still uniform relative to many of their English counterparts, Amish socio-economic levels and occupations have both diversified in the last four decades¹⁵³.

¹⁵³ See (Kraybill and Nolt 2005) for an overview of the rise in Amish entrepreneurship, entrance into non-agrarian workplaces, and the late 20th century changes in national patterns of Amish work.

McKusick's writing here and elsewhere, despite its sophistication in some regards, shows a lack of nuanced understanding about the group of people he was studying. They are essentialized as a monolithic whole and depicted as little more than subjects—a population formed by a confluence of socio-religious factors that built for him a real-world petri dish. Inside that experimental bubble, he saw the opportunity to develop vigorous new data on rare disease and Mendelian¹⁵⁴ inheritance. And he did. And the future of genetic medicine for you, me, and the Amish all benefit from that knowledge. But the Amish are never revealed to be anything more than genetic bodies in the pages of McKusick's writings. Susan Lindee makes similar observations in her chapter on McKusick and his work in the Lancaster area (2005:78-88). She points out archived letters revealing McKusick's assumption and intention that Amish people would not or should not read his reports about their medical states. As objects of study, the Amish move across hugely influential texts like *Medical genetic studies of the Amish : selected papers* (McKusick 1978) with no agency whatsoever. As Lindee notes, they are at once present in the text, even visible in photos and descriptions. At the same time, their “material, intellectual, and emotional embodiment” are wholly absent and all of the data that resulted from their knowledge of their own illnesses no longer spoke to them, nor was it intended to (Lindee 2005:78). Many families agreed to participate with the hope of an answer—an answer to why their children were disproportionately sick. Unsurprisingly, the Amish who gave their time, blood, and DNA to the biomedical community in McKusick's studies found little or no reciprocation.

Rachel Schrock leads me around the corner in a snowy downpour to the *grossdawdihaus* and flips on a few lights on the front porch. “Stay in here, in the downstairs, but only if you don't

¹⁵⁴ Mendelian traits are those that are monogenetic—things caused by a single locus in the genetic sequence that follow Mendel's laws of inheritance. A familiar disease that follows Mendelian inheritance is sickle cell anemia. Sickle cell is caused by a single defective allele and is inherited in an autosomal recessive pattern; both parents must carry the defective allele for a child to be affected.

mind sharing with my sister. She comes in town tonight and she can stay upstairs. But only if you don't mind." She pauses, takes a breath, and finishes, "Sometimes she stays with me when she comes to town." I shuttle a passed-out child into a large bedroom and spend a few minutes peeling back layers of winter clothing. All I can really think about is getting some water on for tea but just as I tiptoe gently out of the room I see headlights illuminating the heavy snow coming down outside. A middle-aged woman emerges, gathers a remarkable number of bags from the trunk of a car, and shuffles up the walk. Even without the car, her long down puffer coat and bright pink scarf make it immediately clear that Rachel's sister is no longer Amish. "Hi, I'm Miriam. Who are you then?" Miriam's speech moves slowly from her mouth with the choppy slur of someone with profound hearing loss. As I offer my elevator speech about Amish health practices, genetics, and so on, her face brightens a little.

Miriam talks about how her parents never really treated her differently when she was very young. They never tried different ways of communicating with her or adjusted for her silent world, so she retreated into a realm of shyness born from never realizing why she was different than the other children. They did take her in to Lancaster social services around age four where she was diagnosed with profound deafness. She could not see well either but continued through Amish school for a few years with no opportunity for enriched learning or extra assistance. About the time she was seven, her father picked her up from school one day with little fanfare and took her over to an elementary school in Strasburg. A speech therapist fit her with basic hearing aids and she began to meet with the therapist once a month. "I loved that speech therapist," she whispers, looking off slightly toward the window in the direction of Strasburg. "That speech therapist was the first one—the only one to give me a voice."

Likely through this link between the Schrock family and the special education services

they found for Miriam, Dr. McKusick found out about her and three younger siblings who shared similar impairments. Researchers visited the house to take some early studies and then, when Miriam was thirteen, she traveled with her mother, father, and three affected siblings to Johns Hopkins. “My dad stayed one night, he had to get back to the farm. But the rest of us stayed for three or four days. They tested us in every way—blood, measurements, urine, IQ tests, vision, hearing, and question after question. There were so many tests.” Closing her eyes to dig back in her memory, she laughs a little at the litany of pokes and prods. Mumbling something about needles, she gets up and crosses the kitchen to retrieve some vitamin supplements from a bag she propped by the sink earlier. This launches her into the story of getting her cochlear implants as an adult—the mixed excitement and physical revulsion of what it was like to begin hearing the world at high volumes most of the time.

I rudely interrupt with a speeding one-track mind: “What happened to all of that stuff at Johns Hopkins? What were the results? Was your family glad you went?” There is a long pause. She exhales quickly and shrugs her shoulders. They never heard anything, she says. She gathered sometime later that a paper had been published¹⁵⁵. But she never received a diagnosis or information on what her ordeal had wrought.

After the snow subsides the next day and everything is heavily blanketed in an immense layer of white, I gingerly check on the possibility that the lane will be plowed so that I can get my car out to the main road. My wish is soon granted and by midmorning I arrive at the Clinic for Special Children and announce, “I randomly met one of McKusick’s original studies last night!” No one seems terribly impressed. After locating a battered copy of McKusick’s 1978 *Selected Papers*, I thumb through until I spot “Cochlear Deafness, Myopia, and Intellectual

¹⁵⁵ Their study was originally published in 1968 in the *Archives of Otolaryngology* but then reprinted in McKusick’s influential work *Medical Genetic Studies of the Amish: Selected Papers* (1978:307).

Impairment in an Amish Family.” Miriam’s case study stares back at me:

13 year old girl ... it was not until age 4 years that the diagnosis of profound deafness was established ... Myopia was diagnosed at age 6 ... a well-developed and alert appearing Amish girl who was able to communicate only when wearing her glasses and hearing aid. Vital signs ... Weber and Rinné tests ... ear canals ... mouth, chest, and lungs ... heart sounds ... secondary sex characteristics ... normal Abnormal neurological findings were limited to impaired visual, audiometric, and intellectual performance. Laboratory study ... hemogram and urinalysis ... cerebrospinal fluid ... chest x-ray and bone survey ... ophthalmologic study ... audiologic procedures ... psychological testing ... (1978:307-308)

Miriam did not exaggerate—there *were* so many tests. In the end, the four affected Schrock kids all had similar eye and ear issues. But the connected intellectual impairments varied and seemed to link here with sex. The brothers were more intellectually challenged than the girls—“The boys appear more retarded than their sisters” (1978:311). I sit there working through the article somewhat puzzled by that piece. Her IQ is reported here as very low in the category “borderline.” But the highly functional woman I sat across from the night before finished college after literally running away from her Amish life. After Lasik surgery and cochlear implants, she works a demanding full time job. Further down in the article, an answer glimmers: “This term [mental retardation] generally implies a primary disorder of the brain and as described, these children may merely display intellectual immaturity as a consequence of sensory deprivation during a critical period of development of the central nervous system ... the primary biochemical defect remains obscure” (1978:311-312). But any sense that Miriam’s diagnosis of intellectual impairment might have been misjudged due to the lack of recognition or intervention in her condition, the same was not true for her brothers. They were, indeed, much more intellectually challenged.

In the end, McKusick’s team could not pin any “precise site of cochlear abnormality due to the mutant gene” or a specific cause of the myopia, although they rule some possibilities out

due to phenotype. But they conclude that this disorder, previously undiscovered, likely follows autosomal recessive inheritance patterns, and that the responsible gene must have arisen from one of four common ancestors in the family seven or eight generations earlier. Genetics was still decades away from being able to test for suspect gene variants or compare meaningful sequence data between individuals. This meant McKusick's detective work to identify heritability heavily relied, somewhat ironically, on inferring genotypes from larger patterns of kinship, genealogies, and phenotype in the Amish community. Here was groundwork for the medical gaze in genetics—one that starts from foundational instructions at the molecular level in an affected individual all the way out to large-scale inheritable health while implicating all the biological kin in its wake (Raspberry and Skinner 2007:356).

In the report about their conditions, the Schrock family appears with the typical sterility of much biomedical literature; the person's body is separated from mind, self, emotions, community, and beyond. The body is treated as a machine that can be manipulated (Martin 2001:19), and referred to in an inventory of test results that push the embodiment of those characteristics further and further from the reader's knowledge. These are familiar manifestations of the body as what Foucault called a "knowable object" in the medical field—one that can be flattened into categories, observed, prodded, and repaired. The report on the Schrock family becomes the contents of a curio drawer of Amish bodies. This underlying practice of physiological reductionism pits culture against nature (Haraway 1978:25); Amish culture—the person, the self, and the *Gmay* by extension of Amish mutual separation—are obliquely portrayed as defective due to the production of flawed bodies. Yet, those flawed bodies are presented as a possibility for redemption in their gift to biomedical science.

McKusick and Hostetler's coauthored piece covering the "background and potentialities"

of studying genetics among the Amish activated decades of genetics work with the Lancaster population (1964). It also sets up Amish bodies as dysfunctional and aberrant products of their cultural worlds. McKusick first outlines basic features of Amish culture-writ-large and includes the long list of characteristics that make them suitable subjects outlined above. This sets up a pitting of culture against nature—Amish history, religion, social configurations, and practices form a “culture” that serves to first corrupt the normative human form even as it allows them to provide the information necessary for human genetic salvation.

Coming off of his detailed list of Amish characteristics, McKusick proclaims that Amish anti-science attitudes are problematic for medical researchers who cannot provide “obvious and fairly immediate practical usefulness [to the afflicted]” borne partially out of their resistance “to alter what is considered the will of god” (1964:214-215). Not surprising for this era, the onus of the researcher to provide or explain such potential reciprocation is not considered. The illustrative anecdotes given involve some families refusing to allow autopsies on their deceased children to help determine possible genetic etiologies and an adult with a form of dwarfism who refused examination. In the text, the Amish are then set apart as rare forms of inbred humans, “experiments of nature.” And such experiments are a “valuable tool” in determining “the normal genetic constitution of man” as well as the “normal biochemical mechanisms and the pathogenesis of common disorders” (McKusick 1964:215-216). In the same moment as Amish bodies are presented as essentially flawed at the molecular level, those defects become highly valued—prized even—for the scientific discovery they denote.

MIM and OMIM

McKusick’s work with the Amish contributed to his development of what is still

considered the definitive compendium of heritable traits—*Mendelian Inheritance in Man* (MIM) (1998). Before his work began with the Amish, McKusick had already published an article that cataloged the known traits mapped to the X-chromosome. In anticipation of what he might uncover in the Lancaster area, his research team began to compile known recessive disorders as well so that they would have a reference work to compare against or add to. In the early 1960s, he decided to parlay that work into a full-blown catalog of all Mendelian phenotypes on the model of his original X-chromosome work. MIM was first published in 1966 and contained over 1,400 entries covering phenotypes from both recessive and dominant inheritance. Thirty-two years later, in 1998, the last print-based edition updated spanned three volumes with over 9000 entries.

McKusick and his team stored much of the information for MIM on computer databases as early as the mid-1960s and he had helped develop computer programs to keep track of linkage studies among family pedigrees. In the 1980s, the National Library of Medicine decided to use MIM as a guinea pig to test a new computer database method that allowed for fast authoring, editing, and searching of the materials. The first online edition premiered in 1985 and was made openly accessible on the internet just two years later—the Online Mendelian Inheritance in Man (OMIM) was born. It is no understatement to say that OMIM has “become the standard reference work on current knowledge not just about genetic disorders, but about the genome as a whole.”

¹⁵⁶ As of January 2014, there were 22,178 entries including gene descriptions, combined genotype/phenotype entries, phenotypes with known molecular basis, phenotypes with unknown

¹⁵⁶ Dates and details of MIM and OMIM history taken from the introduction to the Victor A. McKusick papers from the National Library of Medicine. The digital version of this introduction is located here: <http://profiles.nlm.nih.gov/ps/retrieve/Narrative/JQ/p-nid/307>

molecular basis, and other entries.¹⁵⁷

In 2001, McKusick gave an extensive interview for an oral history of medical genetics project organized by UCLA. He summed up the impact that Amish DNA had on the genesis of MIM and OMIM:

[T]he Amish studies came along, and I wanted to collect a comparable catalog of autosomal recessive traits, because in that inbred population, we expected to find even new recessives that had not previously been recognized. And indeed we did. And to know the new ones, we had to know the old ones. Then for sake of completeness and with some trepidation, I assembled an autosomal dominant catalog ... Those in which the particular mode of inheritance seemed to be quite well established, we gave an asterisk to; and those in which it was in limbo still, we left without the asterisk. Of course, this was MIM, this was Mendelian Inheritance in Man. (Maestrejuan 2001).

In the same interview, he downplays any major connection of MIM to the Amish by verbally repeating the separation of these ventures and subsequently over-emphasizing his ownership of subjects' genetic data and using his own data to create standards in new medical knowledge. In the excerpt below, I have added bold italics for emphasis:

Mendelian Inheritance in Man was *quite an independent venture, quite independent* from the Amish studies. It was *quite independent* from Heritable Disorders of Connective Tissue. It was *a separate effort*. We had a terrific journal club. ... And the journal club was particularly successful, I think, because we had a specific goal, namely, the preparation of an annual review of medical genetics, which came out each year -- it's a quite fat affair; I can show you these -- in the Journal of Chronic Diseases. We seized that opportunity to illustrate particular disorders with *pictures of patients of our own*, or *material from patients of our own, our pedigrees*, and so on, to illustrate the particular points that were being made in the review. (Maestrejuan 2001).

The downplay of Amish bodies as object samples is clear in the few references he allows during this biographical interview—so much so that the interviewer switches her method of reference to that work halfway through from “your work with the Amish,” to the McKusick-tinged, “the Amish study” (Maestrejuan 2001). The implication that McKusick was an

¹⁵⁷ <http://www.omim.org/statistics/entry>

opportunist practicing medicine awash in old-school paternalism is hardly revelatory. His role in the now-infamous case of Henrietta Lacks does nothing but bolster this character sketch. In the HeLa debacle, McKusick was the first to betray the pseudonym and provide the real name of Henrietta Lacks in a widely read forum, the journal *Science*. Later, in the setting of a larger research consortium, he offered to procure blood samples of Lacks's descendants and sent a researcher to do so with no informed consent (despite the fact that informed consent and board review were both standard practice at that point). The female research assistant that did the legwork for him later said, "He was a famous, famous man, he trained most of the other famous medical geneticists in the world. When Dr. McKusick said, 'You go back to Baltimore, get this blood drawn,' I did it" (Skloot 2010:175-184).

McKusick goes so far as to brazenly flaunt the characteristics of his career that would now be considered breaches of basic research ethics. He excuses such paternalism by setting up opportunism as important in clinical research and comparing himself to Isaac Newton's musings on finding small discoveries in an infinite world:

I think that -- yes. I've said several times that when I review my career, it sounds like the confessions of an opportunist, a chauvinist, and a dilettante. Opportunism, you know, is given a bum rap in the dictionary, which defines it as taking advantage of circumstances often without attention to the consequences to others. Opportunism and serendipity are very closely allied, but opportunism is very important in all research, certainly in clinical research. ... the studies of the Amish were, in essence, an instance of opportunism. ... I confess to the sins of chauvinism, parochialism, provincialism, because I've been at Johns Hopkins uninterruptedly for a very long time ... As far as dilettantism is concerned, one might consider that dilettantish when you delineate clinical syndromes, when you study the physics of heart sounds and write a book on that, when you do gene mapping, when you study the dynamics of genes in population groups such as the Amish, and so on. ... Of course, to compare my career with that of Isaac Newton is absurd, but he says that he feels like a small boy playing on the beach and picking up an occasional pebble that is smoother and brighter in color than the rest while all the great mysteries of the ocean go unexplored. He's just picking up a little stone here and there. So I feel like an unabashed dilettante, as well as a chauvinist and opportunist. (Maestrejuan 2001)

What is most relevant here to understanding McKusick's work with the Lancaster Amish as one

of full physiological reductionism and medical gaze? By the 1980s, the Lancaster Amish had been brought into the genetic conversation with no opportunity to speak. Moreover, they had been brought into the genetic revolution with little opportunity to be treated clinically, appropriately, humanely, or affordably.

The Millers

The sunshine feels remarkably energizing despite the frigid temperatures as I slowly cruise up a cleared lane save a few small patches of ice. As usual, I guess at the most appropriate place to park the car and feel the immediate sense of otherness created by *driving* onto a new farm for the first time. Where to park that won't block the carriage house? Straightening my long skirts and head covering¹⁵⁸, I make my way toward the Miller house, careful to wind around icy patches on the wheelchair ramp up to the porch doors. Susie Miller hears my car arrive and meets me at the door, "You must be Martha King. From Amish Kings? With a name like that I wondered about you being Amish here." Chatting straight away, we walk through into the living room. Like most Amish houses in the Lancaster area, the living, dining, and kitchen are all connected as one large room—a living room space with couches and side tables at one end, a u-shaped kitchen at the other, and a large dining table with both chairs and benches in the middle. While kind and hospitable, many Amish do not offer something to eat or drink upon a guest's entering their homes. In many homes I would be offered tea or coffee only after I had been there

¹⁵⁸ As a researcher in the field, I make all efforts to dress appropriately. Not being a member of an Amish church, it would feel unsuitable to wear an Amish-style *kapp*, but I often keep my hair covered on Amish farms, visiting Amish homes, meeting for interviews, and during community observations. I did elect to wear a more formal mesh covering when I attended some events, weddings, and church services. The Amish are adept at reading the associations behind size, shape, color, and style of a covering, and the one I chose was a standard Mennonite-style, white mesh covering. This would signal to any of the Amish I was interacting with that I was a member of a Mennonite church. As is consistent with most Mennonite groups, I wore my hair pulled straight back and under the covering, as opposed to the Amish practice of parting in the middle and rolling along the sides. It was only to these more formal events that I chose to wear an apron dress, although I frequently wore a black, Amish style apron over a long skirt and shirt. The utilitarian nature of the apron was easy to appreciate and I started to wonder why I don't wear one all the time around the house.

for a half-hour or more. Today would be no different as we immediately settle in on the couch to chat with the pellet-stove roaring nearby.

Like many women of her age, the middle of Susie's hair part is wide from decades of training her hair down the middle, forcefully rolling it from above the ear along the sides, and tightly fastening it into a bun with pins underneath the white, heart-shaped Lancaster *kapp*. As soon as a female toddler has enough hair to roll, mothers will begin parting and pinning it, often as young as age two¹⁵⁹ and long before a girl would actually wear a covering from day to day. By the time women are grandmothers, their part has greyed and widened as a physical marker of their years in the community. Susie's hair shows her years of commitment to the white, organza covering gently fastened with a straight-pin at the crown of her head. A black apron and black cardigan sweater cover her long-sleeved navy dress. Susie talks with the typical lilt of the Amish speaking English—a distinctive intonation that includes markers such as frequent glottal stops, placing objects after their prepositional phrases, dropping verb forms of “to be” out of passive constructions completely, and frequent use of common tag words¹⁶⁰.

Susie Miller is incredibly hospitable and kind. She begins talking about her seven children. Five of them were born with the kind of recessive genetic disorder Dr. McKusick was searching for among the Amish. Her look becomes distant when she starts to tell about the days around her son's injury. As though part of her was stepping back more than two decades, the lines around her eyes soften and her cheeks flush. As she is talking, Susie chokes back and clears

¹⁵⁹ When I would bring my two year old along to farms or have her out to play with Amish friends for the day, teenage girls and mothers alike always wanted to fix her hair. Someone would take her to the bathroom or sit her in the kitchen near the sink and use a bit of water to part her thick hair with a tiny-toothed comb. Deftly and quick, her hair would be tightly twisted along each side to the nape of her neck and fastened into pigtails at the back. It was shocking how fast their fingers would form the rows; before she had time to complain, it was rolled so tightly that it would stay in the whole day. The conformity of hairdos being even more drastic than dress style, she would immediately transform with an Amish look and blend in to all of the other kids playing around the house.

¹⁶⁰ Some common tags include “say” to introduce a question or “dontcha know” to end a declaration.

her throat, causing tears to pop from her eyes and flow quickly down her face. Her son was just about eighteen months old then, feeding himself and talking a bit. He was sick and not clearing up, so Susie decided to take him up to the local physician for a sick-visit. They loaded up and on the trip there the toddler fell asleep for a quick nap. When he woke, he had changed. Something was transformed; he was not able to hold up his head or walk. “He was just, he was a completely different boy,” Susie says, “You have to almost see it to believe it.”

They got into the doctor’s office where the surprised physician asked if he was always unable to lift his head or move around much. This mother’s world came spinning in around her as she held a changed little toddler in her arms. It had just been a matter of minutes that her child had drifted off to sleep on a ride to the doctor and suddenly she was unexpectedly being queried with questions about the child’s abilities. “Was he always like this?” the doctor implored. Susie remembers simply retreating into a corner and crying. “I don’t know what happened,” she said. “He was alright when we left home yet,” she said. Susie wept.

In 1989, a journalist from the Wall Street Journal named Frank Allen also chose to highlight the Millers in his piece on a new country doctor who had arrived in the Lancaster area to help children with genetic disorders. Allen wrote of his visit there:

Two barefoot boys with bowl-shaped haircuts and homespun trousers smile quietly at [the doctor] as they sit on a sofa beside their 10-year-old sister, who cannot walk or speak. A younger boy, whose limbs are limp, rolls and flops on the floor. Their mother irons clothes at the kitchen table. Fresh vegetables simmer on the stove. Since 1977, the Millers have watched five of their seven children suffer the ravages of a rare metabolic disease. ...The three children who survived are crippled for life. Despite extensive testing, doctors at Johns Hopkins University in Baltimore and at the best hospitals in Philadelphia didn’t make a correct diagnosis. (Allen 1989:A1)

Susie echoes the same thing in our conversation. The rapidity in her voice divulges timeworn feelings of desperation as she talks about visiting doctors, hospitals, and specialists with her sick children. By the time the youngest affected child came along, Susie and Amos had grown weary

of a diagnostic odyssey that never seemed to pan out. The travel, the expense, and the expectation when participating as research subjects with suffering children had become more of a burden than it was yielding benefits.

Before we had [youngest child] we had gone to John's Hopkins two different times and we'd also gone to Children's Hospital of Philadelphia for tests and we really got no diagnosis at any of those places. Well, when they knew that we'd been involved with Johns Hopkins, they wanted us to take him down there and I said, well, we had several children down there. Four to be exact, and I said, what's new? Oh, well, they're coming farther all the time with this, but uh, I said, right now I want to go home and come to grips with this and accept it.

About a year and a half later, when that toddler she talked about above was three years old, the Millers were in eating lunch one afternoon when an unknown car pulled in the driveway. Amos was splitting his time between his own crops and working off the farm in those days. He had sold his herd not long after his son fell ill, knowing well that his spate of disabled sons left him with a dearth of necessary farmhands (Allen 1989). His unaffected son was comparatively healthy, but allergies kept him from too much farm work. But some farm-chores were still going on, and that day Amos was home because there was hay to rake. He looked out, "someone's coming," he said and added that it might be a feed salesman from the looks of the car. Busy with lunch, Susie responded, "You might as well go to the door, you're better at getting rid of feed salesmen than I am." As it happened, the would-be feed salesman was not that at all. He was a young doctor named Holmes Morton who introduced himself as someone who was studying disabled children. "You better talk to my wife," Amos retorted. Susie remembers, "He said he'd like to talk for us awhile, and, several hours later he was still here."

Holmes Morton remembers arriving at the Millers house as well. In one of his autobiographical stories, Morton recalls pulling up to the house and interrupting the Miller's meal in order to make a plea:

I could see the rusted wheel chair of a child beside the plow in the barn that I walked past and I thought it likely that I had found the right farm.

‘Are you Amos Miller?’ I asked. Amos said, ‘That’s what they say. Who are you?’

‘My name is Holmes Morton. I am a doctor ...’

‘You say you are a medical doctor?’

‘Yes.’ I said.

‘We haven’t heard of you. Other doctors thought they knew about these children too. Have you ever heard of Dr. McKusick? He was here before. He studied our children at John’s Hopkins, spent a lot of money, and couldn’t give us an answer.’

‘Yes. I know Dr. McKusick. The disorder I suspect is not one for which he would have tested.’ I said. (Morton 2012:14-15)

Susie added that Doctor Morton did not even ask for money. They could tell by that “feed salesman car” that he was not one of those “money doctors.” They had never seen a doctor drive an old car like that. What was more, he didn’t even want blood—just a urine sample from the affected children.

‘We didn’t believe him. After 18 years with five crippled children. So many doctors, so many hospitals, so many tests without answers, then, a young doctor knocks on our door and offers to do a test for free. He said he was just interested in trying to help such children. How could we believe him?’ (Morton 2012:15)

Over two decades later, Susie remembers a few of the things Morton told her about himself and recalls that although it seemed hard to believe he’d find anything, there was just *something* about Morton that felt trustworthy. He explained his current studies with disabled children and gave her some of his own biography—how he had been “far from the average student” as a young man, a high school drop out, and later in the Navy before going to medical school. “It was just, uh,” Susie stammers, looking for words to describe the feeling, “sort of a funny thing all the way through and yet there was something about his way—his way of talking that we trust him.”

A weekend came and went after that first time Holmes Morton showed up at the Miller’s house. The following Tuesday, Susie was home alone with her young son when the strange doctor with the beat-up car came ambling up the driveway once again. She did not recognize him at first but then made the connection and met him at the door. After letting him in, she returned

to ironing as Morton settled in a rocking chair by the window. She recalls him blurting out, “Well, I found what I was looking for.” Talking to me, she pauses, shaking her head slowly from side to side. “It was something. I don’t think I’ll ever forget it.” After watching two of her children die, after seeing three of her other children fall into various states of disability, after countless doctors visits, after extensive testing in some of the nation’s top hospitals—after time, money, patience, and expertise had all but run out, this strange little doctor drives up in an old car and knocks on her door with a diagnosis for all five of her affected kids. She purses her lips together, makes a square nod of the head, and says “He more or less started educating us right then.”

Susie and I had been talking for about an hour when I really begin to feel a sweltering heat. It had not seemed so warm when I came in from the bitter air outside cold, but dressed in long underwear covered by modest skirts, long sleeve shirts, an apron, and a head covering, my clothes are now feeling oppressive. I feel on the verge of passing out. Positively lightheaded, I crane toward the back door to search for some relief when, to my surprise, it opens. Freezing air gushes pleasantly into the room, and her son rolls in from behind the glare of afternoon. Tall and lanky, “all legs and arms,” as Susie calls it, he advances across the floor in his motorized chair, a cheerful look on his face and a welcoming draft in his wake. He livens the whole room up; he’s not able to talk verbally but vocalizes quite a bit. He uses a modified sign language to get across some basic ideas or responses and Susie points out that this means he often relies on them (his parents) to interpret for others. Most obvious are clear thumbs up, thumbs down, and thumbs sideways to answer basic questions. As we sit and talk, his legs and arms jerk a bit, but he is also able to perform some smaller, intentional movements with one hand. While that hand is pointing or working to sign, the other waves around a great deal or gets pinned under his leg. All the

while, he gives off an incredibly sweet and friendly disposition. A few weeks later, when I see him for a check-up at the Clinic for Special Children, it is the same. He jokes with the doctor about rival football teams, smiling broadly, and asks that doctor to come out for a visit for his birthday in a few weeks.

From Frank Allen's story to Bunker Hill

As it turns out, that article in the *Wall Street Journal* including the Millers' story was more than a simple color-piece that came and went with the news cycle. In a few inches of copy, Frank Allen shed a nationwide spotlight on this dedicated country doctor for the first time. This solitary, devoted physician was solving a "riddle of hereditary disease" among the Amish out of the trunk of his car (Allen 1989). Morton had begun devoting himself to home visits and hoped to expand upon the small amount of goodwill he had gathered in the Amish community by getting a clinic off the ground. Allen noted that other experts he spoke with at the time saw Dr. Morton's work as a "worthy" but very risky idea, and this risk was likely the thing that made his approach so unappealing to the status quo.

'He is doing something that could be at the cutting edge for developing a model for rural-care delivery,' says Massachusetts General's Dr. Levy. 'But when you make a move like this, your academic and scientific career is jeopardized. It becomes very difficult to get grants, you lose access to the sophisticated laboratories, you sever academic relationships. Holmes will be, at best, on the very outer circle.' (Allen 1989)

At the least, Morton needed equipment—a mass spectrometer—to get any research or clinical work started, but his research proposals to the NIH and other funding agencies were all rejected. His suggestion at Children's Hospital of Philadelphia to start an Amish outreach clinic was also turned down. Looking at Holmes Morton's biography and knowing him now, it's easy to portray him as someone who has never been much of a follower or felt much diligence was

due to the status quo. At the time, however, he was a fresh doctor with three young children to support. Caroline Morton, Holmes' wife and co-founder of what would become the Clinic for Special Children, remembers getting that NIH grant rejection:

So that was a blow. Um, but also it was a blessing. At the time it didn't feel that way. At the time it was crushing because we thought, how are we going to do this? We had sort of hoped that that funding would come through and it didn't. But it forced us to think, you know, more creatively about how else to establish a clinic and get the funds to get it started. And it also helped form the basis of our thinking of how we model the funding for the clinic even now. Uh, that it not be dependent on grants for support that the support from the clinic for it to be successful long-term must come from within the community it serves. And I think that's been sort of a guiding principle for where we look for support.

Instead of aligning himself more closely to a profile that might win him grants, the Mortons looked for funds in the only place left that they could—they began the process of taking out a second mortgage on their home in the Philadelphia suburbs in order to start up clinical services in the Lancaster area. And the clinical *services* part of that was the thrust. As Caroline foreshadows above, this possible alienation from the scientific community, intentional or not, set the Clinic for Special Children toward forging a path into unprecedented cooperation with a patient community and the beginnings of true translational genetics. With the help of the Mortons, the strand of DNA linking together Amish all over the Lancaster area suddenly became more than a research curiosity and Amish bodies were on the brink of becoming more than object lessons in genetic aberration.

Around the time that Frank Allen's article was headed to press, the Mortons had already finished the paperwork for taking out that second mortgage. Most of the money was going to pay for the necessary mass spectrometer from Hewlett-Packard, and they had the order forms for the equipment all prepared too. All that was left was to show up at the bank and sign the paperwork. On September 20th, Allen's article splashed the front page of the Wall Street Journal alongside one of *WSJ's* stipple-drawing "hedcuts" of Holmes Morton with his signature mustache and

bowtie. That same morning, Morton was speaking at John's Hopkins grand rounds and had Susie Miller along as a guest. She remembers a young doctor coming up from the crowd after having read the article that morning and saying to all of them, "I hope you get your clinic." Meanwhile, Caroline Morton's phone rang at the house. And the calls kept coming. "Do not mortgage your house," the callers implored. One woman said she was sending \$100,000; another was sending \$25,000.

And sure enough those checks arrived in the overnight mail. And oh, I mean it was absolutely just amazing the outpouring of support from people who didn't even live in this region. Most of these contributions were from people from all over the country—from New York, California, who had really no interest other than in what the article said. And we went to work right away, you know, establishing what we needed to do to account for all of that.

We went to the bank and said, you know we have a different problem. We do not need to actually sign the papers for the mortgage ... we need to set up an account to manage these funds coming in. And he says 'I can help you with that!' So yeah, it was just sort of overnight almost we had to scramble to set up the organizational structure. (Caroline Morton)

The Mortons weren't the only ones receiving calls, Caroline noted. Because Allen had mentioned Hewlett Packard by name, HP was bombarded as well with people petitioning the company to donate the equipment needed for this work. As it turns out, David Packard had read the article himself and agreed with the suggestion. Conveniently, the Mortons had the order already drawn up for everything they needed to get a little lab off the ground.

Overnight, this country doctor ended up with all he needed to start up in the Lancaster area. He found himself with more than a grant to study a certain set of recessive disorders or a funding pool to enroll a certain number of Amish subjects. Instead, the Mortons had been gifted a pot of unrestricted funds to move his outreach from the trunk of his car into a clinic. After the wave of publicity, Lancaster General Hospital donated some limited office space down at the Willow Lakes Health Center for the Mortons to use until they figured out a plan for their new

operation. Their eighteen months at Willow Lakes gave them the time to draw a circle around their likely patient population. They needed to have access to Lancaster General, the closest hospital for admitting privileges, and they needed to be in the heart of the Plain communities. John Hostetler came on board as one of their first board members and helped them realize that geographical boundary. Where could they serve both the Amish and the Mennonites best? Word got out that they were looking for land.

One of the early positive screens on that fancy new mass spectrometer came from the granddaughter of Jake Stoltzfoos, an Amish farmer living off of Bunker Hill Road, just outside of downtown Strasburg, PA. Caroline remembers Jake showing them a few rocky spots on his land that he could not really farm. He offered to sell one to them at half the value while donating the other half in thanks for what Doctor Morton did for his family and for what they were bringing to the community. “And once we saw it,” Caroline remembers, “it just was perfect for what we thought.” Taking Jake Stoltzfoos up on his offer placed their new clinic in a relatively central spot for most of the local Plain population but also placed them right in the middle of an Amish farm. Their desire to locate and build the clinic “in a manner that made it fit within the community,” could be realized. “We thought it was a comfortable place to be,” Caroline noted, “not only for us to work in, but for families to come here.” In a special article published by the journal *Pediatrics* just five years after Allen’s WSJ piece, Holmes Morton explains how he and Jake’s livelihoods mirrored one another:

When Jake’s mules turn at the end of a row, he often looks to see if I am at my window and waves. We can each respect the work of the other. He knows I measure the usefulness of my work against the usefulness of his. He knows that I measure the success of my work, not in terms of lectures, publications, grants, or income, but in terms he understands. He has grandchildren with the disease that I study and we hope that they can live to work in that field. (Morton 1994:788-789)

With the land procured, an architect in Philadelphia offered his services after having read the *Wall Street Journal* article. The Mortons felt it was important for the structure to go up as a timber frame design. An intentional choice, they felt that erecting it as post and beam gave the Plain community a part to play in constructing the space from the ground up in a very literal sense. In the style of a typical barn raising, the frame of the building was erected by a swarm of Plain volunteers; but “raising” day was not their only outlet. Amish and Mennonite volunteers were there from start to finish during construction, and Susie Miller remembers that they even loaded in the building furniture and set up the equipment once it arrived. Virtually anyone I talked to that had been involved during the construction period had a cache of memories around piecing together the building down a long lane off of Bunker Hill. Not all of these families were even involved with disabled children at the time; many came just for the promise and commitment that Doctor Morton seemed to exude. And some of those families, unfortunately, had to return over the next years. “They had helped build it thinking it was good for somebody else that they knew, but never imagined that it would actually be their own family that would end up coming here” (Caroline Morton). It was not long after that the Mortons bought a house in Strasburg. Plain community members helped transport their belongings to their new home and when they arrived the place was abuzz with people washing windows, cleaning, setting up lunch on the lawn, and ready to unpack all the boxes.

That initial outpouring and groundswell of community support came from somewhere, and it was going to need a great deal to keep it sustained. How the Clinic for Special Children has built a set of practices that have prolonged and multiplied that support will be covered in the next chapter. It addresses questions such as the following: What changes do physicians report having made in their clinical practices and biomedical culture to accommodate Amish patients?

How do Amish community members reconcile clinical knowledge and practice with their collective identities, and are there indications that these aspects of cultural identity are being reformulated as a result of the encounter between clinic personnel and Amish families? But first, I must rewind slightly to come closer to the root of where the ties between CSC and the Plain families it serves began. And by root, I mean to turn back to those finely stitched threads through the Amish community and stranded sequences of DNA that connect them together through both time and space.

GA1 in the early years

Again and again Lancaster Amish genotypes have been combined and reborn. And these genotypes both mirror and arise as a result of Amish commitment to the practice of mutual separation. In chapter two, I defined mutual separation as the outcome when Amish practice persistently pushes toward two horizons of meaning: the trussing of community via the yielding of individual selfhood and the community's explicit practices of separation from the surrounding world. These produce a high level of endogamy and patrilocality as well as kinship patterns that favor high reproductive rates and long reproductive years. Just as McKusick's list elucidated, these factors taken within a founding population will undoubtedly produce a high rate of recessive gene variants. These are real "local bodies" in the sense that Margaret Lock lines them out to be—"the biological and the social are coproduced and dialectically reproduced" (2001:484). And while Lock warns against conflating population biology and social groupings lest we establish a racist rhetoric in our discipline, she all but glances past the exceptional situation found in insulated founding populations. Or more pointedly, the local bodies produced in rapidly expanding yet genetically isolated populations where those bodies are fenced in by

explicit community rules of order that produce and reproduce cultural practice across generations.

In some ways, Orthodox Jewish communities in Israel, Europe, and the United States constitute analogous populations. The Amish founding populations are often mentioned in tandem with Jewish populations due to their similar ongoing production of these culturally-informed, genetically-isolated local bodies. A vast and significant difference between Jewish populations and Amish could be reduced to a simple dynamic: what is the culturally appropriate response to carrier testing and how does that response impact kinship patterns? Most notably, the program of Dor Yeshorim¹⁶¹, begun in Orthodox Jewish communities in the early 1980s, has radically altered the downstream effects of bio-cultural consanguinity. Dor Yeshorim folds genetic screening and carrier testing into culturally traditional norms of matchmaking. All members of the community are screened and put in a database at a young age. When a match query is made, the samples are compared for genetic compatibility; two individuals carrying recessive alleles known to cause disease are not permitted to continue toward union. The program has an uptake rate of 95% among orthodox communities and has virtually eliminated some genetic diseases typically prevalent among Ashkenazi Jews (Raz and Vizner 2008:1362). The Amish, like Orthodox communities, are not averse to carrier testing but have no traditional practice in which to make sense of this kind of community-wide screening or to prohibit unions on a genetic bases as a means for promoting similar change at the population level¹⁶².

Amish couples that do participate in carrier testing typically do so after they are already married. But even with a pair of positive screens, it would be rare for carrier status to impact reproduction. A subset of the Amish informants I spoke with participated in carrier testing either

¹⁶¹ For a full discussion on Dor Yeshorim including consideration of its ethical implications, see (Raz and Vizner 2008).

¹⁶² Note that neither of these communities typically allows nor accepts prenatal testing.

prior to having children or sometime during their reproductive careers. Some of these had “positive” results (carriers), some had “negative” results (not carriers), and some had results where one partner was a carrier for a recessive alleles and one was not. The vast majority of these cited their reason for getting screened came from the health status of a close relative. Many had affected siblings, siblings with affected children, or cousins with issues. Not all of these relatives had genetic diagnoses or illnesses with clear molecular etiologies. Some couples simply saw similar symptoms or phenotypes running through their families. When asked what they expected to gain from carrier screening, this subset invariably gave answers indicating they wanted to know “for the sake of knowing it,” “to be prepared for what may happen,” and “to know if we should get the baby tested right away.” No one specified that carrier status would cause them to rethink reproduction altogether, so I asked directly: “did knowing your carrier status change your ideas about having children or how many children you would have?” This question was met with a unanimous “No,” across the board. An Amish mother of five children gave this typical response:

I just thought maybe, because of my sister’s youngest son, you know? So [husband] and I went and got tested because of my sister. She was convincing, don’t you know?! Glad to know, to tell the midwife there. The midwife could be sure to test the babies straight away, send that test off. Every time I was worried once the babies were born. But then we would get the test back—and you know, I would—well, you know our people, we love children. All of them gifts, God’s gift, what they are. Every one. Even God’s special children, they are gifts—that’s how our people feel. Our days can be very hard but *not* having children on purpose? [shakes head] I just can’t think on that.

Carrier testing revealed that this particular couple was found to both carry a recessive, deleterious variant. In Jewish communities practicing *Dor Yeshorim*, this would have been caught before the courtship really began, and matchmakers would have never cleared this couple to eventually marry or have children. But as typical for the Lancaster Amish, these two met in

the Youngie¹⁶³, both were baptized into the church when they were married, and they had their first child less than 2 years later. Their family has one child affected with a disease caused by their recessive variant and four unaffected children. They are currently beating the statistical odds, but not by much.

Most Amish families don't know their carrier status when they have their first child. But when carrier status manifests itself in the phenotypes of newborn children, future reproduction is not typically slowed or stopped. Many families trend toward typical large sibships even when multiple children have been diagnosed with a disorder. When Holmes Morton first began knocking on doors in Lancaster County, he was hot on the trail of these families who knew one another—that cousin, that sister, that neighbor down the way who has a child who looks like ours. He was hot on the trail of large sibships with multiple affected children. Dr. Morton was hot on the trail of urine organic acids and a genetic monster hidden in plain sight—glutaric aciduria type one (GA1).

When Holmes Morton was working as a fellow at Children's Hospital of Pennsylvania (CHOP), he came into contact with a urine sample from an Amish boy from Lancaster County diagnosed with cerebral palsy. The sample had come in from a smaller hospital, Elizabethtown Children's, and had been sent for analysis at CHOP partially because the child had a history of normal development with sudden onset of cerebral palsy-type symptoms including dystonia¹⁶⁴.

¹⁶³ The Youngie are peer-led youth groups, often referred to as gangs; they are a common location where Amish teenagers fraternize with the opposite sex and begin dating or courtship relationships. The gangs in the Lancaster area are cross-*Gmay* and often mix kids from different parts of the county together. Each group has a reputation—some are for the kids wanting to be “more wild,” some keep things more straight-laced. Like Greek organizations or informal friendship groups on college campuses, teenagers gravitate toward the gang that appeals to them. They are quite aware that a lot of Amish find their future spouse in the gang. Some longer-standing gangs will see children joining up with the one their parents were in; other gangs form and dissolve through the years depending on interest.

¹⁶⁴ Dystonia is typically understood as a movement disorder that causes sustained muscle contractions, repetitive twisting movements, and abnormal posture. In their definition, Tarsy and Simon (2006) point out that dystonia is often confused with spasticity or rigidity. Dystonic movements are involuntary, can be slow or rapid, can change depending on conditions (stress,

This aspect of the boy's medical history intrigued the physicians; despite being diagnosed with cerebral palsy, this was not the typical presentation of that disease. In the lab, Dr. Morton looked for a pathologic metabolite called 3-hydroxy glutaric acid (3-OH-GA) but did not find significant enough evidence to diagnose the boy with anything specific. He had a conversation with a colleague who had recently profiled a patient with glutaric aciduria type 3; they suspected this Amish boy might have the same thing, particularly since the boy's urine organic acids did not seem significant enough to classify his condition as the exceedingly rare GA1. So he and this colleague drove out to Elizabethtown to see the patient with the referring physician. After that experience, Morton remained curious about the peculiar case and decided to follow the trail of glutaric acid out to Lancaster County (Morton 2012).

In June of 1988 he drove out to meet the family, re-examine the boy, and get a new sample. While there, they were informed of many other children in the community who looked just like their son. And just like their son, these kids seemed normal at birth—they met milestones just like most babies until they met with sudden, irrevocable, unexplainable change, usually in the presence of routine illness. Doctor Morton suddenly found himself with a whole list of doors to knock on. One of the first on that list was Amos and Susie Miller's house. Morton was suspecting the Millers' kids and these other children suffered from an organic aciduria, specifically glutaric aciduria type 1 (GA1).

Organic acidurias result from problems during amino acid catabolism. These problems arise due to deficient enzymes that result in dysfunction during the normal amino acid breakdown of leucine, isoleucine, valine, or lysine (Seashore 2009). One side effect of these

posture, environment, other illness, etc.); there are several classifications of dystonia based on age of onset, etiology, genetics, and/or the region(s) of the body that are affected (Tarsy and Simon 2006:818).

acidurias is that non-amino organic acids like 3-OH-GA, showing up in the urine, make it relatively easy to detect conditions on a biochemical level. The urine specimens that Morton collected that summer going door to door in Lancaster County “contained wildly varying concentrations of glutaric acid,” but he did find “small amounts of 3-OH-GA in other specimens from the first case, and in Amish children” from the other families (Morton 2012). Although the molecular etiology, the pathophysiology, and even the full biochemical makeup of the condition was still undetermined, by September of 1988 it was clear that GA1 was relatively common in the Lancaster Amish community with all major surnames represented in his sample.

In a lecture covering the history of his struggle to pin down the biochemistry of these glutaric acidurias, Morton details the fits, starts, failures, missteps, and small victories that came along through the first decade of his work with the Amish (2010). Looking back at that time as a fellow, he laments the lack of sensitivity in the wet lab process and lack of specificity in the standards for reporting results to referring physicians. He had noticed the breakdown in the system and recalls his first occasion for meeting Dr. Victor McKusick to bring this issue to McKusick’s attention.

Dr. McKusick, like the 99% of physicians who sent this test to CHOP’s metabolic lab, reviewed the results of these evaluations saw a report of “Normal Organic Acid Screen,” and did not know *how the screening* had been done or the limitations of the test. In my opinion this screening program was worst than insensitive, it, in fact, caused most cases of organic acidemias in Pennsylvania and elsewhere to be missed, rather than diagnosed. (Morton 2010)

Morton recalls that these earlier tests archive an absence of positive results for disorders that just a few years later would be confirmed to be common among Plain populations through an expanded newborn screening program using tandem mass spectrometry headed by Dr. Edwin Naylor. “If today I went through the wet-lab dictations from 1986-1988, I would find many names of my current Amish & Mennonite patients with these organic acidemias, ‘screened for

metabolic disorders’ and reported have *normal* urine organic acid screens” (Morton 2010).

Journalists and print media have called Holmes Morton a sleuth, a medical Sherlock hunting down the diseases of the Amish. There is something attractive about these metaphors—snooping around the genes and living rooms of Amish worlds—but the metaphor hardly does credit to the reality of GA1 and its historical trajectory. This trajectory, in a Latourian sense, begins with the true “social” as Amish cultural worlds began to fray and ravel in the presence of GA1. In the late 20th century, these GA1 families with sick children were pushing against the boundaries of the *Gmay* in multiple ways: traveling to tertiary care centers with sick children, taking in large medical bills, and facing the questions of disabled community members who would clearly not laminate well into flattened labor roles or reproductive expectations¹⁶⁵.

Latour tells us that resuming the work of reassembling the collective (in the wake of such fraying) “traces the social as associations through many non-social entities,” and if we pursue this tracing systematically, we may end up “tracking back to the shared definition of a common world” (Latour 2005:247). What developed out of the CSC over the next two decades was a stitching of translational genetics into those frayed ends at the boundaries of Amish cultural worlds. As they would have approached any technology, Amish communities approached medical genetics patiently and with consideration. And as with any technology, medical genetics must speak back to the community through its effects on common practice. Understanding the network of actants moving through this slow adaptation toward dialogic participation—the Amish in translational genetics and translational genetics in the Amish—allows us to move Morton out of a role sleuthing his way through the genes and urine samples of Amish bodies and instead see him as a catalytic actor in a large network of actants/actors who co-produce the story

¹⁶⁵ The incongruity of disabled adults and what it means to be part of the laminated collective in Amish cultural worlds is discussed further in chapter six.

of Amish participation in biomedicine.

Critical to later successes at CSC were these early understandings of GA1 that arose from tracing through this network beyond just biochemistry and potential molecular etiology. Dr. Morton emphasizes that his understanding of GA1 first changed from spending a great deal of time listening to what he saw as the *real experts* of the disease at the time—the Amish parents of GA1 children who had been paying attention to its every manifestation for decades. These mothers and fathers never had a real diagnosis for this disability well-known through caring for those afflicted within the community, and some had spent years trying to find one—thus traveling often outside of their community’s literal and cultural boundaries for answers. Despite diagnoses of “Amish cerebral palsy,” the parents repeatedly insisted, “the babies seemed normal,” before those days when their child changed forever. Over kitchen tables and on covered porches, the parents told Morton of the sudden change in their babies during naps, overnight, or in the space of a few hours. Many of the kids had a concurrent illness, perhaps an ear infection, diarrhea, or a fever brought on by a mild virus. Children with cerebral palsy don’t go from normal to nonverbal in the space of an afternoon nap.

Morton made two radical moves around the time of founding CSC. The first was a willingness, despite trepidation, to forego the typical career path. Above, a physician quoted in Frank Allen’s 1989 article points out that Morton would be jeopardizing an academic and scientific career. “Holmes will be, at best, on the very outer circle,” that physician noted (Allen 1989). It was a radical move to step away from such a professional trajectory, but even more so to step away from those recently established research patterns utilizing Amish bodies as mostly research subjects. Even noticing the limitations of screening procedures as a fellow in the lab foreshadowed Morton’s innate ability for critical observation. Motivated by a drive to improve

medical care, he stepped out from behind accepted, systemic protocols. That othering from biomedical culture's expectation did place him on the outer circle—but not just the outer circle of medical genetics. It also placed him on the outer circle of Amish cultural worlds and particularly the fraying strands of those worlds. His second radical move was to recognize the shift in symbolic capital that move implied for his profession and to employ those critical observation skills as a node within the network of Amish GA1. Afflicted kids went from normal to irrevocably changed in the course of an afternoon; Morton decided to concentrate his efforts on determining *how to prevent the injury from occurring in the first place*. As simple as this sounds, it was an entirely new discernment for the disorder.

Conclusion

Holmes Morton, MacArthur genius and Albert Schweitzer Award winner, is quick to proclaim that all of his work at CSC “evolved from the knock on Amos Miller’s door” (Morton 2012:56). Today, thanks in large part to the tracing of the networks around GA1 and CSC, the disease is considered treatable, the associated brain injuries are considered avoidable, and children across much of the country are screened for GA1 at birth¹⁶⁶. There is a prospering new generation of Amish children with GA1 that are running around farmyards and attending Amish school with all of their peers. Due to the kinship patterns discussed above, it is unlikely that the prevalence of GA1 in the Lancaster Amish community will diminish anytime soon. But the phenotypic outcome of the disease has been radically altered by moving the investigation out of biomedical structures and into Amish communities of practice.

¹⁶⁶ GA1 is listed as “screening for the condition is universally required by Law or Rule and fully implemented” on the National Newborn Screening Status Report released by the National Newborn Screening and Genetics Resource Center. See here for the full report (<http://genes-r-us.uthscsa.edu/sites/genes-r-us/files/nbsdisorders.pdf>).

As a result, CSC is an ideal setting for investigating interactions across difference that occur between patients and practitioners in terms of conceptualizations of healthcare, illness, and the body. Among the Amish, medical genetics stimulates negotiation over particular technologies and thereby drives potential shifts in practices involving new healthcare models. The clinic is also a venue for cross-cultural negotiation inasmuch as its practitioners strive to operate within cultural regulations and economic structures of the community including their removal from systemic structures of biomedical research. Above, I pointed out that the conversation between Amish communities and medical genetics was similar to their negotiation around many forms of technology. Based on limits of practice dictated by mutual separation, Amish communities approach medical genetics slowly and with consideration. And like with any technology, to find success, medical genetics must speak back to the community through common practice. This dialogue moves us into the next chapter.

Chapter 5: Clinical and Cultural Contexts in the Genomic Age

Introduction: Medicalizing Amish Bodies

This section will carry out the aim begun in the last chapter by examining how local Amish cultural identities and standards about technology get modified in light of their desire to access modern genetic medicine. The case study material allows me to further explore the dialogic interchange between Amish patient families and biomedical practitioners in the clinical setting. This will require consideration of *how practitioners at CSC accommodate aspects of Amish cultural worlds in the organization of their clinic and what effects this accommodation has in both communities of practice*. To begin, I describe the clinical setting and employ the GA1 case study to discuss the clinical encounter. This will set the stage for discussing translational genetics as a lens for understanding how the collective sense of what it means to be Amish in the Lancaster settlement is being elaborated in response to the availability of CSC.

It may be useful first to reiterate the idea of laminated group identity and play that against a way of thinking about medicalized bodies. The identities of Amish communities of practice, contentiously laminated or sedimented in practices around mutual separation, create a collective sense produced and embodied by a set of actors through those joint activities and commitments (Holland and Lave 2001). Unlike some communities of practice, Amish church districts do not come together for the purpose of collective action toward others; through mutual separation, their group activities and commitments loop back to consume the set of actors enacting them, thus

creating a solidified community that makes itself conditional on the cohesion of the whole. The use individual Amish selves make of mutual separation as world making, quite literally comes to define individuals' ideas of themselves *as* a “whole social being” (Bourdieu 1984:478-479).

During this earlier discussion, I pointed out that despite this lamination of collective and individual, some degree of individual expression and mindset are maintained, but the purposeful self-subordination of those individuals to the community identity is “the fundamental key that unlocks many of the riddles and puzzles of Amish life” (Kraybill 1994:30).

One tool that may be useful in further understanding the interaction between the Amish *Gmay* and the world of biomedicine is to consider them in light of Scheper-Hughes and Lock's “three bodies” (1987) and what this conceptualization might tell us about the Amish and medicalization. The “individual body” in this model is understood as the body-self, the phenomenological sense of the body living apart from other bodies. The “social body” is understood as a symbolic canvas, where the physical and cultural meet and provide us with understandings about society. The “body politic” is understood in poststructuralist terms as the regulation and control of bodies at the level of the polity. These three bodies—the individual body, the social body, and the body politic—allow for overlapping theoretical considerations as well as providing a useful model for thinking about perception (Scheper-Hughes and Lock 1987:8).

Where might these bodies overlap for the Lancaster Amish and the staff at CSC; where might they differ? The idea of suppressing of the individual in Amish society should not suggest that they hold no concept of being as separate from other humans. What needs to be countered is the “western notion of the individual as a quasi-sacred, legal, moral, and psychological entity, whose rights are only limited by the rights of other equally autonomous individuals,” (Scheper-

Hughes and Lock 1986:14). For the Amish, this is not a total absence of personhood as Reed claims with regard to the Gahuku-Gama (1955) but more akin to Japanese emphases on acting within a social relationship instead of autonomously. In that case, one's aim is to perform the social identity given by relationships in the social context and dutiful conforming to the whole is considered a sign of strength (Scheper-Hughes and Lock 1986:15). Moral authority among the Amish pushes individuals to strive toward full immersion in the *Gmay* as a faithful member—the priesthood of the believers.

What develops when the Amish social body engages a biomedical system based on Cartesian ideals that fully separate bodies from one another, the biological body from the spiritual self, and body systems into mechanized parts? “Medicalization inevitably entails a missed identification between the individual and the social bodies, and a tendency to transform the social into the biological” (Scheper-Hughes and Lock 1987:10). Genetics, in some ways, provides an intriguing case of this potential for the practitioner to miss the patient's connection to a social body due to the transparent impact that social practice (culture) can have on genotypes (nature) and resulting phenotypes (nature/culture). The high prevalence of certain diseases with molecular etiologies among the Lancaster Amish results directly from trans-generational commitment to mutual separation. Indeed, mutual separation—the yielding of individual selfhood and separation from the surrounding world—creates a bio-cultural feedback loop where genotypes are reproduced (sometimes to the point of detriment) as a result of social practice. But this feedback loop alone, as a singular problem, was the kind of jump-off point that launched men such as McKusick into Lancaster County. It nods at the interplay of social practice and biology but still distills them down into a biological phenomena paired with a social dysfunction in a one-direction causal relationship.

It is likely this reductionist approach would have eventually detected molecular loci for many genetically based diseases in the community, given advances in technology and understanding in medical genetics. What is more equivocal is whether this approach would have eventually uncovered disorders heretofore not understood as having molecular etiologies and then led to the development of efficacious treatment protocols. In retrospect, this seems unlikely. Over twenty years since Holmes Morton knocked on the Miller's door, CSC has placed traditional biomedical concerns for the individual body atop explicit care for the social body in their patient population and its associated body politic¹⁶⁷. Sensing and making strides toward attending to the interconnections between and among the three bodies has enabled a dual achievement: success for the Clinic for Special Children in the realm of finding and treating genetically-based diseases in Plain populations around Lancaster and success for the Lancaster Amish community at large for finding real help, answers, and building new practices within the community around their special children.

In Chapter 3, I introduced seven factors that weigh heavily in Amish decisions around healthcare modalities: cost of care, continuity of care, appropriateness of care, word-of-mouth referrals, craft practice, perceptions of natural origins, and knowledge dualism. Looking more closely at today's Clinic for Special Children, I will first consider the built environment and cultural artifacts in and around CSC and the active roles these actants play in the clinic's ability to be in positive cultural dialogue with its surrounding community regarding these seven factors. As discussed in the last chapter, encounters in fields of Amish pluralistic health require actors to participate in negotiations across realms of difference and always wrapped up in cultural artifacts—in this case, medical or otherwise body-related technologies. Cultural artifacts, space,

¹⁶⁷ Note here that the regulatory "body politic" for an Amish *Gmay* is the community itself. This will be discussed in Chapter 6.

and materiality mediate effects of the group on outside actors and play a dominant role in the cohesion of Amish group identity. After this section, I will move into consideration of the explicit alterations CSC has made to clinical practice in the co-production of small-scale translational genetics among Plan people in the Lancaster area.

CSC: the Built Environment and Cultural Artifacts

The road twists from both directions between hilly farms and hairpin turns up to a slightly battered wooden sign standing unobtrusively at the end of a long, straight lane. Even in the late fall, a thick grove of trees beyond neatly maintained fields shields a view of the Clinic for Special Children. Miles away from traffic or retail, the only sounds floating through open windows might be a team of mules being worked in one of the adjacent fields, a clip-clop of hooves coming in on the lane, or the frequent drum of a woodpecker. Whether the corn stands sending tassels to the sky or ice crunches all along the way, the lane up to the clinic remains quietly untroubled. It holds, however, countless arrivals and departures that are anything but. As parents make their way up that lane behind the elegant gambol of buggy horses or in seats of commissioned twelve-passenger vans, they arrive and depart yoked with emotions ranging from relief from a successful treatment to distress for a dying child. They carry their babies quietly up that lane because, for many, this may be only place that can help. They carry their babies quietly up that lane because, for most, they've come to know The Clinic for Special Children as a place where their families are approached with the same qualities valued by their communities: deliberate patience and constant persistence. It is a place that crafts concern for every part of that child's medical story—a mutated gene, an affected body system, a suite of symptoms, the weight on the family, the impact on the *Gmay*, and the implications in the whole community.

The building rises in the hillside with all three floors exposed along the back but the driveway curves around uphill with the main entrance on the second, and main, floor in the front. This is not unlike the way many barns are built into hillsides or use earthen mounds to allow for access above the ground floor, and it is not the only way the clinic resembles a barn. With a simple façade of blue-grey wooden siding trimmed with deep red millwork and a matching red door, the structure is built on a massive post-and-beam skeleton with its beautiful buttresses exposed along the front porch. Their sturdy beauty continues inside; cleanly milled, vertical beams meeting wide posts and brought together by visible peg-construction. Each wooden peg, having been applied by hand, divulges a craft of skilled workmanship. At the end of the main hallway, the building opens up and the ceiling vaults to a windowed cupola. Gentle curvature of wooden supports criss-cross the air above. When the early morning light streams through the windows and quiet drapes the clinic like a winter blanket, this area echoes the sacred silence of grand cathedrals. A cross-shaped nave with no altar; here stands a place where the knowledge of science and the sagacity of faith meet on a daily basis.

Quilts hanging the walls absorb the echo of the warm, wooden floors. Peppered throughout the building are striking, and often moving, paintings created by Sarah McRae Morton. The heavy canvases elicit rural farm life and ethereally disconnected gazes alongside Amish lives. The main hallway also hosts gift quilts and photo collages of the clinic's early years including building construction. The liminal space of a standard medical clinic¹⁶⁸ has been nearly negated—not simply scrubbed clean, but denied existence in the beginning. The liminality I refer

¹⁶⁸ Hospitals and clinics can be theorized as liminal spaces as they remove patients from flows of typical time and space in favor of encapsulated environments. Patients are often dwelling in between various states of illness, diagnosis, protocol, and powerful dictations from unseen (medical or administrative) powers. Long et al. discuss how these spaces impact patients by becoming grounds for switching out major elements of individual identity—someone moves from healthy person to cancer stricken, from immobile person to person with a new hip, etc. (2008:73). The built environment in these liminal spaces often reflects these kind of symbolic and functional roles for the clinic: sterility, interchangeability, universality, and hierarchy.

to here is the intentional shaping of space used by clinics, hospitals, airports, casinos, to induce the ambiguity and repetitive familiarity of spaces without time. These spaces serve narrow functions and often actively attempt to remove their users from the outside world or larger contexts which may interrupt or complicate the goals within. At CSC, white linoleum floors, windowless rooms, melamine cabinetry, imposing overhead lights, and metal exam tables have been passed over for warm wooden planking and bright twelve-pane windows, clean white walls with ivory trim, and the constant peek and exposure of thick wooden beams. Many of the exam tables are constructed from wood and each exam room is outfitted with stations of wooden cabinets. The concept of CSC serving as more than a clinical/research space and instead as a *medical home* is first amplified through the physicality of its space.

The built environment extends into other areas of materiality in the clinic. The vast majority of patient families in the waiting room are dressed plainly in accordance with their church and districts. With the exception of a single Amish staff member, everyone in the office is already separated from the patient population by one aesthetic stop. With the patients and their families dressed in plain garb—be it Amish or Mennonite—and the staff dressed in English clothing, otherness at a visual level is already marked. None of the physicians here wears a white coat; none of the nurses wear scrubs. No one has a nametag or an ID badge—just the occasional stethoscope draped around the neck. Doctor Morton often sees patients wearing his trademark bow tie, askew and sometimes unfurled at the end of a long afternoon. Doctor Strauss darts around from room to room sporting a grey woolen vest over a dress shirt with no tie. The white coat as a professional uniform is not needed. Patient families know these physicians; their relationships extend beyond a yearly visit or a chance meeting in town. Not only do many of these patients require frequent care, relationships are fostered. These doctors and nurses make

house calls, they interact at auctions, and they are invited over for dinners, weddings, and funerals.

The staff dress comfortably, but they also dress in a way that reflects potentials of their positionality relative to their patient populations. White coats are not necessary at CSC because the symbolic capital that they signify is irrelevant. We saw in chapter three that Lancaster Amish avoid biomedicine for primary care for reasons of cost, perception of doctors as greedy, and concern to value the knowledge of God over the knowledge of man. Many Amish regard doctors as avaricious. As patients who pay out-of-pocket, they are well aware of the full price of services in a clinic or hospital if they have interacted with one. At the same time, most Amish are not knowledgeable of dynamics that govern service rates; some assume that the majority of a bill goes straight to the billing physician him or herself. When coupled with the quick and impersonal manner with which physicians are often forced to deal with patients in a hospital setting (where Lancaster Amish would be most likely to encounter biomedical doctors), they are seen as inherently greedy individuals full of self-aggrandizing motivations. Removing the white coat serves by taking away a cultural artifact that symbolizes this kind of excess.

When talking about the original plans for the structure and raising of the clinic's building, Caroline Morton acknowledged that "the design as well as the way we built the clinic was really intended to invite the community to be a part of it." Intentional considerations for the built environment and material culture in the clinic started with this impetus and continue to manifest themselves on a day-to-day basis. Some of those manifestations are large, like the clear parallels of Amish building construction and location on the corner of farm property. As practice picked up at CSC over two decades, smaller-scale considerations of representation on the part of the

staff at CSC began to take place on a day-to-day basis. And those considerations of representation quickly branched into practical structures of how medicine is practiced there.

Environments of Care and a Medical Home

Every morning the doors are unlocked, the lights warm up, the machines begin to whirl, and the waiting room anticipates packs of women in apron dresses toting little children in black-suspended coveralls or dark pastel play dresses. The work of translational genetics is set to begin. It is tempting to use a metaphor of CSC's straddling biomedical and Amish cultural worlds—one foot in modern medicine, one foot in Amish culture—but this is not truly apt. CSC does not remove any part of itself from being a product of biomedical systems; it does not step outside of biomedicine. Instead, CSC insists on practicing biomedicine, and particularly clinical genomics, in new and different ways. This allows the clinic to engage Amish communities as a biomedical actor while still participating in a dialogue around the categories that typically exclude biomedicine from Amish consideration. Some of these changes at CSC happen beyond the reaches of consciousness for the staff; just as practice becomes sedimented in any cultural world, small shifts make manifest the possibility of a biomedicine that steps back from its own position of power to attempt real translation across cultural divides. One of the first and most overarching concepts that plays out in practice at CSC comes from a recognition that medical care does not start and stop at the door of a clinic. That alone is no major revelation; cultural competence guides and public health workers also begin with this kind of logic. But there are two ways this precept is put into play differently at CSC: practitioners recognize the clinic as an equal actor in the network of health for any given patient family and major revelations at the

clinic can often be credited to understanding the natural history of disease. Let me address these two ideas in turn.

“Cultural competence” models tend to look at the non-dominance of biomedicine in indigenous or plural medical systems as a reflection of ignorance or inability to assimilate into the *right* way of understanding the body; subsequently, research papers get written and allopathic approaches to treatment are molded into educational units that can be implemented by a clinician at the point of care or in public health outreach. One organization, Windows of Hope, operating in the Ohio settlement, performs just this kind of colonialized outreach. A partnership between researchers in the UK and physicians in Arizona, the project aims to detect and characterize inherited health problems among the Amish¹⁶⁹. In 2012, they performed a qualitative study measuring genetic competency to create data that might aid in creating “culturally appropriate intervention and prevention strategies” for Amish communities and focused in part on the community’s pinning causation for heritable disease to sinful behavior (Cassady 2013). This kind of approach shows a colonial characterization of Amish society—a poorly educated, arrested community that if made to understand biomedical approaches would be able to solve some of its health problems.

In contemporary medical anthropology we tend look at pluralistic structures as generative of culture, not as an impediment to development by way of biomedical conversion. In other words, the goal would be to understand Amish health as a system that can be worked within, instead of pushing standards of education and what gets referred to as “cultural competency” in the healthcare encounter. This is not an approach that an organization like Windows of Hope

¹⁶⁹ See (<http://www.wohproject.org>) for more information on Windows of Hope. WOH includes no clinical care. Their project includes data gathering on local families, molecular and biological studies, and entering that information into a database.

seems willing to mobilize¹⁷⁰. It is, however, an approach that sets CSC apart from many other researchers and clinicians. CSC recognizes itself as playing a role within a larger network of Amish health and Amish life. They do not diminish the Amish as uneducated spiritualists, they do not aim to proselytize a biomedical message, and they do not disparage other parts of the Amish plural health system to patients unless they believe a practice to be dangerous for their patient or in direct contradiction to the care being received at the clinic. DNA becomes less something to be managed and more something woven into Amish cultural worlds. By extension, CSC recognizes itself as a piece of that cultural picture.

In my study, I found Amish understandings of genetics to be relatively nuanced despite the dearth of scientific education. This was particularly true among families with farming backgrounds. Heritability was a familiar construct to many people and not once did I hear language or narratives that would classify the presence of genetic disorders as fate or a punitive act from a vengeful God in response to sinfulness. Instead, rhetoric around special children shows them becoming touch points for faith-based disciplines of acceptance, of finding joy in Plain life, and of understanding the trials of earth-bound humanity. In fact, the Plain communities coined the term “special children” to indicate the feelings of extraordinary witness these children bring into the community. The Mortons later took this term on for the name of their clinic. Thinking of these children as special is not to diminish the difficulty families have in raising children with significant physical, medical, and developmental needs or the financial and emotional burdens this can place on families and districts alike and on affected family members as they grow older. But it points to a different set of concerns for Amish families.

¹⁷⁰ I note that doing research for the sake of research is not what is at issue here. But the unique aspects of Amish genetics, their general unfamiliarity with biomedicine, and their relative disinterest in hegemonic power structures makes them strong targets for exploitative research. In addition to the treatment-research hybrids being built at CSC, there are some (non-clinician) researchers who work in these communities without exploitative aims or ends. The most notable is The Amish Research Clinic run out of the University of Maryland.

Genes alone don't determine outcomes; expression and phenotypes can be mitigated by environment. For example, you may have genetic risk markers for heart disease, but the expression of those genes will be influenced by your smoking history, ability to procure a healthful diet, accessibility of exercise, or proximity to ecological agitators. These “environments” that influence gene expression are often built by and of *culture*—the cultural worlds that people interact in and create through their interactions. The socio-biological implications of how behaviors meaningful in someone's cultural world determine health risks and health outcomes are very real. Recognizing and adjusting for this concept has been key to the success at CSC, and this recognition has resulted in a shift in the ways both medicine and research gets conducted there. In other words, the physicians recognized that it is not just those outside environments of the patients that are important in understanding the interplay of genetics and environment—it's not just what their patients are doing *out there*.

The staff and physicians at the Clinic for Special Children approach their work with the understanding that biomedical culture itself becomes part of the environment implicit in manifestations of disease and thereby impacts health outcomes and phenotypes in their patient populations. It starts in the familiar form and function of timber framed supports—not a doctor's office, *a medical home*. It spreads into each interaction, each ill child, each fretting parent, and each time a practitioner walks into an exam room. At each one of those entrances, the liminality of a medical clinic is not just negated, but inverted. The physician must see more than just a pediatric genetic problem to solve; the physician must see parents, family, and the entirety of a church district all wrapped up in the coil of that little one's DNA. On the flip side, Amish patient families—not necessarily limited by their educational backgrounds—are being offered biomedical approaches as a legitimate option through culturally appropriate, experiential

interaction between cultural worlds. The subsequent level of genetic and scientific knowledge was sometimes impressive among those families that had been treated at the Clinic for Special Children over a long period. Here is one father of a GA1 patient describing their dedication to following the CSC treatment protocol:

[Y]ou know as well as I do that when you do tests, and the subject is inconsistent from one test to the next, you don't have an accurate analysis. You just don't. When you're done, there's so many variables in there ... you can't see what progress you've made with this program if not everybody's following it the way it was given.

Coming face-to-face with the community history of disease results in CSC placing itself *among* the myriad actors and actants connected in the network of Lancaster Amish medical genetics. In turn, those histories, when incorporated into the clinic's knowledge base, become another way they consider the importance of health practices outside of their doors. One example of this has already been alluded to in Chapter Four. When talking about those early days in Lancaster County, Holmes Morton always emphasizes that his understanding of GA1 changed from spending time listening to the Amish parents of GA1 children. Morton began to recognize these parents as the real experts on what the disease looks like, how it manifests, symptoms, timelines, phenotypes, and outcomes.

The experience of talking with the Amish mother ... shaped the course of my medical career. Her observations about Glutaric aciduria in her five affected children provided the first evidence that the brain injury could be prevented. What she told me about the natural history of the disease has defined my approach to medical practice and research. (Morton 2012:54)

These wheelchair-bound Amish kids who could not speak or control their bodies had been showing up in times of dire sickness at Children's Hospital of Philadelphia and Hopkins for

decades. “It was a dark time for those MSUD¹⁷¹ families and GA-1 families,” notes Kevin Strauss, the current medical director at CSC. He continued, “They were, they had sick kids, disabled kids. They were repeatedly getting flogged by the systems in Philadelphia, driving down and getting substandard care and paying a lot of money for it.” Many in the medical establishment pinned the issues of these children to a problem from or at birth—thus the term Amish Cerebral Palsy. But the parents repeated, “the babies seemed normal,” before those days when their child transformed forever. Across kitchen tables, parents told Morton of the sudden change in their babies during naps, overnight, or in the space of a few hours.

Morton made a radical move around the time he was learning from these parents, driving around the countryside for urine samples, and founding a clinic. This move began with a willingness, despite trepidation, to forego the typical career path. A physician quoted in Frank Allen’s 1989 article pointed out that Morton would be jeopardizing an academic and scientific career. “Holmes will be, at best, on the very outer circle,” that physician noted (Allen 1989). It was a radical move to step away from such a professional trajectory, but even more so to step away from those recently established research patterns utilizing Amish bodies as mostly research subjects. As explained in chapter 4, even noticing the limitations of screening procedures as a fellow highlighted an innate ability for critical observation motivated by stepping out from behind systemic protocols to attempt improving medical care and foreshadowed the same kind of work being implemented by design at CSC. That othering from biomedical culture’s expectation

¹⁷¹ MSUD is Maple Syrup Urine Disease, an organic acidemia that follows autosomal recessive inheritance patterns and occurs at very high rates among Lancaster-area Mennonites (~1/380 births). In many ways its history and treatment successes at CSC mirror that of GA1 in the Amish. The metabolic crises that happen with these patients require intense hospital treatment. Combining comprehensive care at CSC with appropriate intervention at Lancaster General, “the overall hospitalization rate for [CSC’s] MSUD cohort is currently only 0.4 hospital days per patient per year” (Strauss and Puffenberger 2009:530). This indicates a decrease from an average of 7 hospital days per patient per year over the last 20 years and reflects a financial savings for the Mennonite community of approximately “4.3 million annually—nearly 3 times the clinic’s operating budget” (Strauss et al. 2012:e2).

did push him to the outer circle—but not just the outer circle of medical genetics. It also allowed him to approach the outer circle of Amish cultural worlds and particularly those fraying strands in Amish fields of biomedical technology. Subsequently, he recognized the shift in symbolic capital that such a move implied, and employed those critical observation skills as a node within the network of Amish GA1. Doing so allowed for full consideration of the natural history of these disease states. These kids went from normal to irrevocably changed in the course of an afternoon. Morton decided to concentrate his efforts on determining how to prevent the injury from occurring in the first place. As simple as this sounds, it was an entirely new discernment for the disorder.

Understanding GA1

Kevin Strauss first visited the young Clinic for Special Children in 1993, just before he went to medical school. As a budding young scientist with a college degree in biology and physical chemistry, Strauss was deeply struck by the impact among Plain communities, but he also came away from that experience with an intense desire to learn more about the science of what Morton was up to.

It was the idea of a physical basis, an understandable, controllable physical basis for childhood disability that absolutely captured my interest, that to me was a stunning realization. Because I had never thought about it that way, not in the way of chemical forces, or physical forces that can be understood and controlled from early in life to prevent a child from being severely retarded or the difference between a 110 IQ and a 40 IQ ... It's a difference that *makes* a difference.

Strauss went on to complete medical school at Harvard and a residency in general pediatrics at Boston Children's Hospital. In 2001 he returned to the Clinic for Special Children, coming in as a second doctor at a vital time to ease the clinical burden for Morton, to bring fresh eyes to the clinic, and to spearhead peer reviewed publications on the research and clinical findings at CSC.

Up to that point, Morton had little time to publish his mounting knowledge about GA1 in the scientific literature. This caused some in Morton to appear as something of a “maverick and an outsider, because serious scientists validate what they know through publication and peer review” (Belkin 2005). That swiftly changed with Strauss on board; the clinic has since published or been co-authors on eighty-three articles and counting. Strauss, now the medical director at CSC, has long worked with GA1 and now takes on all of the new cases.

I keep circling around GA1 as a focused case study to simulate the feeling of its ambiguity in the Clinic’s history. The publication trail coming out of CSC illustrates how their knowledge of GA1 progressed, even at times when they were wrong and readjusted their course. GA1 has been a flagship and ultimate quest as well as an enigma and frustrating puzzle. In some ways its agency was firm: drawing the Mortons into contact with Amish cultural worlds, rapidly stealing futures from young babies, instantly changing families as it struck silently during a nap. In other ways its agency remained slippery: leaving a rare individual uninjured, affecting some more profoundly than others, failing to reveal itself under the cloak of cerebral palsy. Kevin Strauss has a video he uses in some presentations and in the class he teaches on genetics at Franklin and Marshall College. It is a home video of a (non-Amish) toddler just after suffering the irreparable, devastating brain injury associated with GA1. She is prone, her body stiff and contorted at strange angles, and she is letting out an unnerving wail somewhere between pain, confusion, and distress. Toddling around, smiling, playing with her dad’s cell phone just days before, now she is trapped forever in a body that does not work with a brain that has sustained irreversible damage.

Before I continue with co-creation in these two communities tied together by genetics, let me take the opportunity to pause the vulturine circle around GA1 by fast forwarding its

microhistory and revealing what decades of research and treatment have uncovered at CSC. This provides an opportunity to understand the biochemical, genetic, and medical realities of GA1 before exploring how CSC manages those realities in light of Amish cultural worlds.

GA1, or glutaric aciduria, falls into the category of inborn errors of metabolism or inherited disorders of the organic acids—categories of disease that imply both the biochemical and the underlying genetic basis. As Amish populations sailed across the Atlantic, their population narrowed, bottlenecked, and survived amidst the tumult of separation from the mainland. Sometime in the 1730s, a ship of emigrants from Switzerland arrived carrying one John Lapp and his wife. Along with their Anabaptist faith, these two European Amish also each brought with them a change of a single allele, on a single gene, on the nineteenth chromosome. It was biological chance that the Lapps both carried around up this same change and ushered it into an emergent group on new shores¹⁷². On chromosome nineteen there is a gene called GCDH. It is located from base pair 13,001,942 to base pair 13,010,812.¹⁷³ And along that stretch, both of the Lapps had single missense mutation, in the same place, causing the same amino acid substitution.¹⁷⁴ These variants did not bother either of the Lapps because they were both carriers and neither were affected¹⁷⁵. GA1 follows autosomal recessive inheritance patterns; both parents

¹⁷² Using detailed genealogical records, the Lapps have been traced as the common ancestor of the current-day Amish with the deleterious variant for GA1. There is no way to know for sure that either of them had affected offspring and there is nothing in the historical record to indicate that they knew about an illness that ran in their families. Due to the reliability of Amish genealogies, the Lapp conjecture is considered a relatively safe one.

¹⁷³ See the entry in Genetics Home Reference on GCDH (<http://ghr.nlm.nih.gov/gene/GCDH>)

¹⁷⁴ More specifically, the Lancaster Old Order Amish GCDH variant for GA1: 1296C>T, A421V. There are other variants that cause GA1 in the worldwide population; OMIM details documented mutations tied to the disorder and Genetics Home Reference (link above) indicates that over 150 variants on GCDH have been reported worldwide to cause GA1. But Lancaster Amish cases, thus far, have all been homozygous for the same change, indicating they spring from the same founding variant. For more on the allelic information, the OMIM entry can be found here (<http://omim.org/entry/608801>).

¹⁷⁵ A balancing statement should be made here to recognize that the facts of this biomedical case are themselves complex cultural products, situated in historical trajectories, and possible to undergo change well into the future. This narrative reflects a biomedical set of truths at the time when this is written and should not necessarily be taken as a statement of those same truths in the past or yet to come. Similarly, projecting 21st century understandings of genes, amino acids, variants, and the like onto the

must carry an altered version of the gene to create an affected offspring. Generally, that gives their children a 25% chance of being affected by the disease in question, 25% of coming out totally free from the genetic change, and 50% of quietly carrying on the disease to the next generation.

No one knows for sure if the Lapps had any affected offspring, but their genetic variant on GCDH moved on, swimming in a new and shallow gene pool. Nearly 100 years after the Lapp's arrival, the Lancaster settlement came together as pockets of Amish families sprinkled through southeastern Pennsylvania joined under one Bishop. In chapter two, I noted that such a shift brought together a number of founders as familial control over socio-spiritual practice was relinquished and picked up by the church as a singular body. It also continued to bring together founders in the genetic sense; boundaries of the community were ideologically in shift but endogamy continued to rule the day. The hesitance of the second wave Amish emigrants during the 19th century did little to alleviate any bottleneck when they passed over the Lancaster settlement for areas further north and west.

By the late 20th century and early 21st, that single variation on GCDH had reproduced its way through time, striking Amish babies before they completed toddlerhood, and saturating the Lancaster Amish genotype. Between 1989 and 1993, Holmes Morton began screening urine for signs of the disease. During that time he checked 1,232 Amish children for biochemical characteristics of GA1 (Strauss and Puffenberger 2009:523). But the genetic basis found on GCDH managed to stay under the radar until technology caught up with it. Dr. Ed Naylor's supplemental statewide screening did just that in 1994; as long as midwives could convince

1730s should be recognized here as a narrative choice, not an implication that these conceptualizations could have or should have been useful at that time.

mothers to participate, the new screen would catch GA1 within a few days of birth and typically well before it caused catastrophic injury. By 1999, The Clinic for Special Children was sequencing GCDH in-house (Strauss et al. 2003: 39) and still runs a confirmation when a patient comes in off of newborn screen results. Currently, the combined worldwide frequency of GA1 stands at 1:100,000 (Hedlund et al. 2006:87) in the general population¹⁷⁶. GA1 strikes in the Old Order Amish around Lancaster at roughly 1:300 births. Between 2006 and 2011, the era of this fieldwork, CSC took on ten Amish babies born with GA1.

If a baby has two copies of the variation the Lapps passed into the Pennsylvania Amish community in the 1730s, that baby will end up with a deficiency of the enzyme typically produced by GCDH—glutaryl CoA. When working properly, this enzyme helps break down amino acids such as lysine, hydroxylysine, and tryptophan. Without a proper enzyme, those amino acids and their immediate breakdown products begin to build up toward abnormal levels (Genetics Home Reference 2014). These excesses can lead to injury of the basal ganglia system—the areas of the brain responsible for voluntary motor control. Referred to as a metabolic stroke, acute neurological deterioration, or striatal degeneration, these brain injuries are quick and irreversible.

Notably, GA1 has a small number of other features associated with it, including macrocephaly, the possibility of abnormal prenatal brain growth (Hedlund et al. 2006:87), and subsequent potential for distortions in vascularization of the brain. GA1 children, therefore, are at a highly-increased risk for subdural hemorrhage and/or retinal hemorrhages after minor head trauma (Strauss et al. 2003:41) such as falling off of a rocking horse or tripping while learning to

¹⁷⁶ The figure for GA1 frequency in the general population fluctuates somewhat in the literature; this “worldwide” figure was determined using newborn screening data from 2.5 million infants.

walk. These hemorrhages are classic presentations of child abuse and have led to the investigation of Amish parents in more than one case. This aspect of GA1¹⁷⁷ has become one of Holmes Morton's personal battles; he has served on the Attorney General's Advisory Board on Child abuse and served as an expert medical witness to clear Amish parents in the face of what the medical establishment considers clear abuse.

Brain injury occurs before the age of two for almost all babies affected by GA1 and typically happens in the presence of additional bodily stress associated with fever and dehydration. The result of a GA1 injury can vary in severity from individual to individual, but it typically starts with loss of body control, loss of muscle tone, and sudden abnormal movements that can be mistaken for a seizure. After this initial attack on the brain, the more permanent manifestation of the brain injury starts to set in, characterized by crippling dystonia.

Dystonia interferes with talking, swallowing, airway reflexes, breathing, and voluntary movements. Abnormal muscular forces deform the developing skeleton and can dislocate joints. Non-specific medical and surgical complications caused by dystonia are the primary reason for office visits, hospitalizations, and surgeries in affected patients. Respiratory problems are the major cause of early mortality. Dystonia in GA1 is difficult to treat. Medications that normally act on striatal receptors are generally ineffective. (Strauss et al. 2003:46-47)

Several patients survive to adult life remaining wheel-chair bound and requiring constant assistance. These patients seem to have relatively normal cognition, respond to commands, but have trouble talking or performing tasks because of poor muscle coordination and severe spasticity. (Hedlund et al. 2006:88)

Once this kind of pathophysiology is realized, it becomes easy to see why Morton's revelation brought on by paying attention to the natural history of disease seems simple and logical.

Treating an injured GA1 patient is costly as well as emotionally and physically draining for all

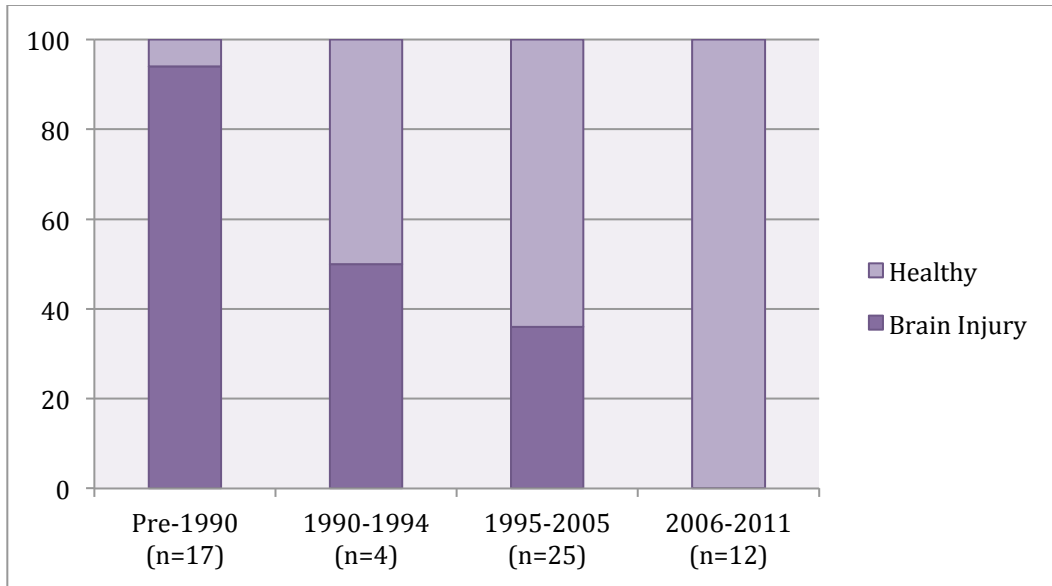
¹⁷⁷ This is not the only disease occurring at a high rate in the Amish community with potential outcomes that mimic child abuse or shaken baby syndrome. One of the most well-known cases involved a long legal battle with Morton facing a team of other medical experts convinced the young baby girl was shaken to death. Morton, along with help from a neuropathologist, was eventually able to outline the physiological and genetic evidence proving that her injuries stemmed from a form of hemorrhagic disease of the newborn and related vitamin K deficiency found in the Amish population (Morton 2012:128).

involved. Spending twenty-four months *preventing* the injury from happening in the first place just makes good sense. But how?

Reading through the published articles coming out of CSC as they developed their protocol provides a clear history of medical knowledge in production¹⁷⁸. Morton's early ideas started with a protein-restricted diet and attempted control of secondary illness or fevers (Morton et al. 1991:89). Twenty years later, Strauss et al. published a paper summarizing their current treatment protocols with a focus on their use of a premixed formula for GA1 babies (2011). This formula was devised to compensate for the breakdown problems of those amino acids mentioned earlier. Specifically, the authors show that the presence of lysine encourages the build-up of cerebral glutaryl-CoA and that controlling this factor should be a "central goal of GA1 management" (Strauss et al. 2011:100). They had been tinkering with amino acid intake in their patients since the mid-1990s, but Strauss noted in a lecture to his undergraduate genetics class that literature published in 2005 on another founding population with high numbers of GA1 convinced him that the issue was centered in the brain and the solution would involve issues of regulating amino acid transport. The best way to restrict lysine is to give its receptors a hearty adversary: the newest formula puts "lysine in direct competition with arginine at the blood-brain barrier," but this has to be done judiciously because lysine can't be totally done away with either. "This is the 'double jeopardy' of treating most organic acidurias: reducing tissue toxin accumulation always entails the risk of selective amino acid starvation" (Strauss et al. 2011:99-100). Formulas were once mixed by hand in a small room at CSC or partially by the parents themselves. Today, a manufacturer of amino acid modified medical foods produces the

¹⁷⁸ The production of which, of course, has not stopped. Current etiological framings as they are presented here are not the end-all but examples in the continued production of biomedical conceptualizations of health, illness, and the body.

formula¹⁷⁹ for use in the clinic. When Holmes Morton first drove into Lancaster County, the injury rate for Amish GA1 kids was 94%. Early dietary and screening developments dropped that number significantly. Population newborn screening along with refined diets, lifestyle, and treatment protocols closely monitored at CSC has totally eliminated injury in the Lancaster Amish population.



Percent reduction in GA1 related injury rates at CSC

Graph redrawn from (Strauss et al. 2012:e12); appeared in the original with the following caption: “Brain injuries causing severe dystonia decreased from 94% to 36% by 1995. Since the introduction of a new glutaric academia type 1 lysine-free, arginine-rich medical formula, designed by clinic doctors in 2006, there have been no brain injuries among 15 consecutive glutaric academia type 1 patients over 28 aggregate patient-years.”

CSC breaks those GA1 treatment protocols into “well-day,” “sick-day,” and “emergency” management. These all revolve around adjusting the amino acid transport issues, reducing

¹⁷⁹ The formula developed and tested by CSC can be viewed here: (http://www.medicalfood.com/glutarade_junior.php). In cooperation with this company (Applied Nutrition Corporation), the most recent cohort of patients at CSC were provided the premixed formula at no cost as a trial of the product.

protein, routine vaccinations, and eliminating (or preventing) fevers and dehydration¹⁸⁰. But these medical articles do little to illuminate the challenges to daily, social practice inherent in such a protocol. How does a mother prevent fever in a child under the age of two? Put more bluntly, how does a mother prevent fever in a child under the age of two when she lives in a densely populated community with wide personal contact, participates in a plural medical system that typically avoids pharmaceutical fever reducers, manages multiple older school-age children as vectors for disease, and contributes to allomothering within her *Gmay*? Not to mention her having to give up nursing (or pump exclusively), protect the child from minor falls, readily endure multiple hospitalizations, and willingly vaccinate not just her affected child but all of the family members.

These examples suggest how CSC must encompass the ways that medial care does not start and stop at the door of a clinic—patient environments and communities of practice can and will be transformed by the incorporation of biomedicine. In order to make that change a positive one, biomedical cultures must be willing to come to the table with their own changes just as soon as Amish standards for care and technology must be willing to slowly bend.

I think, I think we made progress in GA-1. I think we made progress. It's been, that's the disease, that's the disease that got Holmes in the clinic, it's certainly the disease that got me most interested in the clinic initially, it's what I devoted most of my time too. ... It is really interesting to look back to when I came out of residency and what I imagined my career would look like and now, now look what we're doing, what we're involved in. ... It's malleability; it's flexibility. Our ability to change and grow and evolve in a way that adapts to the needs of the community, the needs that we recognize in the community.
(Kevin Strauss)

This adapting “to the needs of the community” is not just lip service. There are three substantial categories that illustrate the kinds of changes CSC has made in their clinical practices to

¹⁸⁰ Full treatment protocols for all three of these categories are outlined in (Strauss et al. 2011:96) and include details on major dietary goals, clinical goals, laboratory goals, and full procedures during hospitalization.

accommodate Amish cultural concerns. All of these recognize that medical care sits within, not above or outside, the environments that impact patient outcomes; and therefore, CSC must be more than a medical clinic but a central *medical home* for the community. These three major categories are as follows: patience and an adjusted model of clinical care, the blurring of lab-clinic divides, and the economics of a self-pay system. The next three sections will elaborate on each of these areas.

Patience: More than a Virtue

They used to every now and then invite our children to come play with them when I was over working at the clinic or running errands or whatever, trying to get things started. And our children just thought it was fantastic you know, to spend the day on an Amish farm! And they had girls the same age as our girls.

I'd gone over to visit and you know the children were sort of playing around with their children [we] were talking and I said 'We're trying to figure out, you know, how to get this clinic started.' And feeling sort of frustrated on how it was going to come together and finding support.

She said, 'Well, if it's meant to happen it will happen.'
And I thought to myself, *how can she be so patient?*

... And many times when I've felt like we were up against a brick wall and I wasn't sure how we were going to get to the next step, I mean it just looked impossible, and sure enough, a door would open, something would happen that we had no idea could possibly happen and that's been the case all the time. (Caroline Morton)

In 1539, Menno Simons wrote: "Our weapons are not weapons with which cities and countries are desolated ... Christ is our fortress; patience our defense ..." (1983trans.:81). This Anabaptist patience is cited as a central virtue in Amish faith as described by sociologists and historians in the Amish studies literature.

[A]mish people demonstrate uncommon patience as they make their way in a perilous world. They do not skip from one thing to the next, but stick with traditional answers and approaches. When they are faced with problems, their first instinct is to wait and pray

rather than seek a quick fix. Indeed, ‘the quick solution, the simple methods, and the rapid cure’ that characterize ‘our instant age’ are dangerous ... demanding immediate solutions signals a lack of trust in God, and, in their view, patience is the best way to show acceptance of God’s timing. (Kraybill et al. 2010:xiv)

The central role assigned to patience certainly grows right out of rhetoric used by the Amish.

I’ve heard patience preached in church, invoked in interviews, and instructed by mothers. Patient consideration typifies many interactions, from relationships within the *Gmay* to broader decisions around technological change.

This thinking about patience must be a component of embodied identity and color the material realities of what it means to be Amish interacting with the world. Looking for how those fields interact with patient humility, I kept returning to *time*. These two are rarely hitched together. Time and patience are only mentioned together once in *The Amish Way: Patient Faith in a Perilous World*: “Even time, bending to the spirit of *Galassenheit*, is yielded rather than forced” (Kraybill et al. 2010:61). The two are tied together in a brief paragraph in *The Amish*:

Patience is one expression of humility and *Gelassenheit*. Amish spirituality values patient waiting rather than rushing to conclusions and forcing results. Indeed, the perception of time in Amish society, regulated by the changing seasons, is slower than the speeding seconds tracked by digital clocks. Patience is the implicit, invisible message conveyed by every Amish carriage that slowly makes its way along roadways as cars streak past it. (Kraybill et al. 2013:67)

And while I agree that patience *instructs* Amish experience of time, I don’t agree that the characteristic fully *forms* that experience. Instead, Amish networks of technologies, craft, and social practice construct of a common sense of “Amish-time” that invests in the spiritual practice of patience.

As an outsider, I found some elements of Amish time baffling—there was a constant tug between an incredible efficiency of getting an enormous amount of home and farm work done during the daylight hours, pushing against the relaxed calm implied in the quote above that

permeated the way most people narrated their days. Time appeared to be fully engaged and never wasted. And, without that waste, time always seemed to be something people worked patiently within instead of against. On one of my first trips to the field, an Amish neighbor told me that she felt sorry for the English because of how we spend our time. “English get very busy doing nothing. Televisions and things for just sitting, but always so rushed. The English I sell to out at market rush, rush, rush, and complain. Say, you should all just slow down, you know?!” Here rises a temptation to romanticize Amish life again as somewhat *timeless*, as existing arrested in a better time and space when the work-a-day world was not infested with Facebook wormholes or Netflix binges. Amish people do “waste” time doing things that might be considered otherwise unproductive—but if most of those activities are not directly productive, they tend to be social. Visiting, playing outside, recreational pursuits are virtually never solitary activities; if not producing goods, producing the health of the family, or producing income, Amish typically are left producing the community of practice.

Earlier, I discussed time in talking about the bounded space of the church district; for example—their use of transportation, influenced in part by speed/time, shapes how Amish bodies can move within and around the boundaries of the geographical limits of the community. By extension, these speeds help shore up the boundaries of the communities of practice. Travel is slowed by horse-and-buggy technology; the lack of electricity puts certain boundaries on the workday and minutes devoted to daily tasks are rarely reduced by time saving technologies. Communication, for example, is never instant; with visits, circle letters, and phones that are placed only outside the home, collaboration with others in the community moves at a distinctive speed. Busy from dawn to dusk, Amish attention to task is deliberate. Understanding the

importance of time instructed by patience is a crucial lesson in understanding their interactions in plural fields of medicine.

Amish time becomes quite apparent to me seated with a family in the waiting room at Lancaster General Hospital. I have brought in an Amish mother who sits fretting nervously with a young baby's socks. Two of her other kids play quietly among the potted plants and she shoots the occasional side-glance at packs of white coats scurrying by. I doubt the waiting itself feels uncomfortable to her; I know she's not one to sit still for long with a busy house and seven kids, but if you can make it through three hour church services partially delivered in your third language on benches with no backs, you can certainly handle waiting for a doctor. I ask her why she is so nervous. We're here, after all, for an expected test and there is really little reason to worry. Her baby's health has been very good. "It makes me uncomfortable," she murmurs quietly. "Their jobs are to help people? But it is a kind of unkindness to all us out here the way they move so quickly. They talk so fast, the way it took longer to get here than we will spend in with the doctor. I'd rather stay home and get a visit [from a chiropractor]."

I return to Lancaster General the next morning to go on hospital rounds with Dr. Strauss. Ten-month-old Hannah Wittmer was admitted for a fever night before last. Her mother, Mary, thinks it was likely from teething and everything has cleared now. We enter the room and Mary's face brightens visibly to see him. Kevin sets down his bag and sits down next to the both of them, giving Hannah a large smile. "How are *you*?" he says to Mary. She lets out a large sigh and laughs a beat, "oh, you know, rather not be in this place. But glad she's gotten the fever out of her. She's fussy but happy today." This is the second time Hannah has been hospitalized for an infant fever; Kevin reassures Mary that they were doing the absolute best thing by bringing her here. This is when I expect him to delve further into Hannah's recent episode, but it's a good

while before he gets to the subject. Mary rocks a bit in the chair while he asks about her other kids by name and what's going on with her husband's farm work. They talk about another relative that is a patient at CSC, the recent snow, and how often she's getting out for church. Eventually, he covers one eye with the head of his stethoscope and peeks out from behind it. Hannah lets out a little squeal. She's not so friendly when he goes to check her ears, but it passes quickly and he gets through a quick exam while talking to Mary about getting one more blood draw before he discharges them. Hannah is looking great, he says. His voice cracks a little; he puts his fist up to his mouth briefly and clears his throat.

Hannah *is* looking great—she sits on her mother's lap in the large, blue hospital chair. She's wearing a little mauve dress with a flat dressing-gown style apron overtop that snaps at the neck. Her fat cheeks are not to be outdone by her arm rolls and the majority of her silky baby curls are raked into a tightly rubber-banded whale spout on top of her head. As any healthy 10-month old would, she shrieks, grins sheepishly, does a little bit of peek-a-boo, and wails with discontent while prodding her pesky gums with fat, drool-covered fingers. Hannah is also in a prime window for injury from GA1. These are the days when Mary Wittmer and Kevin Strauss must both be the most vigilant caregivers possible to keep her brain safe.

Dr. Strauss finishes up with the Wittmers and moves on to another patient while I stay behind to keep Mary company until her husband arrives with a taxi van to take them home. Her first worry is keeping Hannah on fever reducers for the next few days.

It's really hard for us to go medical. You know, I mean, we don't, I just hate giving Tylenol unless it's absolutely necessary. And now she's in here and she was on Tylenol and she doesn't even have a fever. And he wants me to keep on giving it to her. I'm not sure if I want to or not.

... [But] sometimes you just have to let go, let God, or think that God's going to take care of it. This is the best way to go with a GA child. They say a fever is good, you know, to help burn out the sickness or whatever. But with GA, that's the last thing we want.

As our conversation continues, I learn that the Wittmers have never really used doctors before. They don't see a family doctor. The family does have a chiropractor and a neighbor cousin very much into herbs who helps Mary with making tinctures or knowing what to use on the kids. "We use natural things," she says, "vitamin C, Echinacea, those kind of things. We go for that before we go for the doctor." Even Hannah, in addition to close monitoring at CSC, gets probiotics added to her formula, cod liver oil, and an herbal immune booster. This was one of the things she was worried about when they started care at CSC. "We like to do things our way," she says. But she soon learned that CSC would live up to its reputation. She feels like they understand something about "Amish culture" that other English people are not so quick to pick up on and brings that back to the time they spend with her. "He takes time to explain every little detail, every visit lasts up to an hour. And he's talkin' most of the time! (laughs) Which is very interesting, you know. You get to understand it a little better."

Hannah's GA1 was caught by state newborn screening, her results were forwarded to CSC, and the Wittmer's got a call from Dr. Morton when Hannah was seven days old. She seemed quite healthy, so Dr. Morton let them stay the weekend at home and make the hour-long trip to the clinic on Monday afternoon. At nine days, Hannah and her mother were introduced to Dr. Strauss and he's been walking with them in her journey toward the goal of an injury-free second birthday. The next week after that hospital visit, I am trotting along all afternoon behind Dr. Strauss at the Clinic for Special Children. We spend about an hour and a half with an English mother and her GA1 baby who drive in from out of state and toward the end of the visit, one of the nurses pops in and says, "The Wittmers are here."

Hannah has a cold and ran a low fever the night before. Mary had phoned the CSC doctor on call and Dr. Rider told her to administer Tylenol, start the sick-day formula, bring Hannah in

first thing, and to call him back if the fever did not come down. Mary had done all of those things and the fever had subsided. After unhappily suffering through the nurses drawing blood, little Hannah sits curled up in a huff on her mom's lap. A lot of the young patients here have to have blood drawn at their visits and most of them know the nurses are their adversaries in this losing battle. Some parents tell me that their kids start crying as soon as they turn down the lane to the Clinic because they know the needles are coming. "She hates getting gixed. She just knows if Christine is coming at her, it's the gix." Dr. Strauss comes in and Hannah brightens a little after blinking a fat tear from one eye. He sits right in front of her, smiles, and takes one hand. She looks up and sneezes right in his face.

He scoots back and relaxes in his chair after swabbing his face with a Kleenex. Just like during our hospital visit, Dr. Strauss and Mary Wittmer talk about a few of topics at length: the taxi ride down, her cousin's baby, her neighbor's turn to host church this coming Sunday, and so on. They continue to chat for a bit while he slowly moves in to begin examining Hannah. "I'm torn up. I know it's just an illness, Dr. Strauss. I know that. I could take care of it in my others. But I'd go. I'd gladly go to the hospital. But it's just an illness." Hannah's breathing is slightly labored and her cough sounds tight. He carefully listens to her chest noises with the stethoscope for a long time—the room is silent except for her shallow breathing—and then gently percusses a few spots on her back. "I feel my ulcer acting up," Dr. Strauss laments as he takes the stethoscope from his ears and loops it around his neck. "This is about as sick as we would let her get without putting her in the hospital." Looking worried, he decides she'll only go back in if the fever spikes but must stay on sick-day formula and Tylenol every 6 hours until dinner-time tomorrow. "But you have to call me. You have to trudge out in the snow and call me either way to let me know how she's doing."

Dr. Strauss scoops up Hannah and places her on the wooden exam table. She grabs at the paper liner and seems pleased with the crunching noises it makes in her fists. He points out how her hair is thick and asks Mary how often she has to cut Hannah's nails. "I just cut them when they get long—the same as everyone else's!" she exclaims. "It's a great sign of growth," he explains. "She's protein restricted, but this getting teeth, the beautiful hair, her nails growing—those all point to protein sufficiency. Years ago GA1 kids were not growing so well before the new versions of the formula." Hannah, a rosy blob, smiles back from the table. He sits her back a bit on the paper and lets go with both hands to check her for axial tone. He does not take his eyes off of her but explains out loud that the paraspinal muscles have to constantly correct for gravity. Small basal ganglia injury would show up in a baby this age if she could not operate her hands and keep her posture and strength at the same time. As Hannah starts a drunkardly lilt to one side, she corrects herself automatically, returning to a centered posture. She reaches for her toes but goes a little too far—almost face-planting on her own lap but then snaps back up straight with a smile. She takes a toy from my hand while sitting straight and lifts it to her mouth. "See," Kevin says, "she can correct herself, can make a direct grasp with her hand while sitting and you see no jerking back or falling. If her basal ganglia was damaged, even enough that we might not notice much otherwise, she would have trouble operating her hands and keeping her posture strength."

He turns and opens his laptop to print out a personalized treatment plan from Hannah's chart. Mary scoops up Hannah, scrunches up her face and says, "Dr. Strauss? I worry about this. This here—" pointing to a spot in Hannah's head, "so my brother thinks we should get a cranial therapist to look at this." He places his hands gently on Hannah's shiny hair and palpates her skull briefly. "I'll be right back," he says before stepping out of the exam room. She places the baby down on the floor and Hannah starts to grapple at the chair leg and scoot toward a toy

hanging out of the diaper bag. Kevin returns; he sits next to Mary with a medical illustration of the infant skull and traces a line along the coronal suture in the picture while explaining that the little ridge she feels is totally normal.

It might be that it was not as noticeable with your other babies or maybe we've made you hyper sensitive. But I'm—I'm what you call a *scientific doctor*. And from what we understand in medicine, this is a normal ridge for someone her age. It's possible that a cranial therapist would do her no harm. But don't forget that she's at a higher risk for bleeding. From a scientific point of view, her skull is normal and we would not want to mess with it or press on it too forcefully.

Hannah is desperately trying to pull herself up on Kevin's pant-leg and repeatedly sneezing into the fabric. He laughs. "So no cranial therapist could fix that?" Mary asks. "It's not something that needs to be fixed. It's really not. It will grow right into place," he responds. Mary immediately comes back with, "okay, okay—so what about this," as she draws a bottle out of the diaper bag and hands it to him. He looks it over and hands it to me. "Bio-kult" probiotics. "It's okay," he says, "okay at the levels you're giving it to her. Don't overdo it, okay?"

Hannah's results from the nurses blood draw an hour ago have posted in her medical record¹⁸¹ from the lab across the hall. And Dr. Strauss launches into some nutritional counseling as he tinkers on the laptop with her new formula needs and daily protein intake from table food. All the while, he's answering Mary's rapid fire questions about what Hannah can eat herself and what she should not. The new plan is to allow for 2grams of protein per day from table food; he leans out the door and calls for Christine to bring in a photocopied handout of protein levels in typical foods. "Two grams. Two grams only!" he proclaims as he hands her a print out of her new nutritional plan and treatment summary, custom adjusted to reflect everything he's observed about Hannah's state today.

¹⁸¹ CSC uses a custom EMR (electronic medical record) system that was designed and implemented by the lab's director, Dr. Eric Puffenberger. It's optimized for an Apple OS environment and seamlessly incorporates clinical findings with lab reports, imports hospital reports, includes lists of all the disorders they see at the clinic, and enables them to do cross-sorting of symptoms and etiologies to aid in diagnostics.

In the hospital, Mary made special note of how long these visits are and how much Dr. Strauss talks to her. All of that talking has clearly had an impact on her knowledge about GA1 over the last ten months. In an interview, I ask her to explain GA1 to me the way she would explain it to someone who was totally new to the disease and knew nothing about it.

Your body can work off the excess lysine and tryptophan into energy and growth, and that's where hers is blocked and then it turns into glutaric acid. I guess that just makes it easier for the brain to get damaged if its blown up by glutaric acid, so they try and keep that down. And try and keep her fevers down. If you are sick and you get a fever, that's your body trying to heal that part of your body, so all the sugars, all the energy goes to that part of the body. So your brain doesn't have that much, you know, there's not much sugar or much energy there. And that's very dangerous for her because that makes her brain weak. And it makes it easier for the injury to occur. I guess it's like a stroke or something? And the part of your brain that gets damaged is as big as your small finger, the tips of your finger. And that can affect so much.

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It's just genetic. I don't know, how can you explain it? That's the only way I can explain it. You both have to be a carrier of this gene. Apparently your body is made up of thousands, or, not millions, of genes.

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I come at the clinic and I see these other patients come in? I really think GA is not bad at all. I mean, as of now, you know, she has a good chance to have a normal life but some of those children do not.

Mary's narrative about GA1 bears the mark of her *time* at the clinic. She admits freely that she did not understand anything about the disease before that phone call when Hannah was just a few days old other than that GA1 kids these days get quarantined at home for some time. In other words, her only reference for the disease in the community was the impact it had on the ability of those families to interact in a typical social manner. But she goes on to explain how much she's learned over the last ten months, not just about tryptophan and lysine, but about how genes tell your body to do things, how doctors use things like ultrasounds to see inside your body for research, how germs get passed but "not so badly" when kids are vaccinated, and how they can use machines "to read your blood, to see your genes." Kevin Strauss feels like working with these younger families makes his job as a science educator in the exam room somewhat easier.

The new generation comes in already more accepting of the Clinic by reputation, and they also come in less set in their ways. He emphasizes that he must recognize the patience inherent in Amish ideas of time and work within that sense in order to reach the Amish population. And youth goes a long way toward his effort to bring people into his particular strand of biomedical intervention in their larger plural system.

[T]he specter of supernatural healing is still all around us, it's a sea, we come in contact with families all the time, who have been treating things with poultices and charcoal and magnets. The differences though, with the families we see with newborns, is that we ... have an opportunity to teach them a kind of scientific approach to managing a disease from an early age and do it in a way that is not intimidating for them, and that's one of the real tricks of what we do. ... explaining things to people, explaining scientific concepts about disease management that are, that people can understand¹⁸² and understand it within the constraints of their own education, their own belief system but that are not condescending or pandering or inaccurate. And that is not easy to do. That is not easy to do.

The frenzied pace of most medical settings is considered inappropriate and unfriendly by most Amish; that feeling gets both respected and reflected in the clinical set-up at the Clinic for Special Children. Time informed by patience counts. The day at CSC is designed so that patient families spend as much time as they need to with their physician—and a portion of that time goes toward continuing important social relationships. Typical sick-visits last between 45-60 minutes, but it is not unheard of for visits to go on for two hours or longer. The physicians see just a handful of families each on a given afternoon in clinic. This pace not only aids in remarkable continuity of care (something we may all like but the Amish are particularly sensitive to), that continuity also provides a natural forum for fostering essential patient education with a population that stops school at 8th grade across the board. When discussing the genetic counseling and general biological education they get involved in during clinic visits, the

¹⁸² In the clinic, Dr. Strauss typically uses a large number of farming or agrarian-related metaphors to explain genetics, heritability, and body systems to patients. This is sharp contrast to my ethnographic work observing medical geneticists at UNC. These doctors tend to use sports, battle/war, or copyediting metaphors when explaining genetic testing and heritability.

physicians would invariably turn the conversation back to what *they* had to learn out of these situations from the patients. They remain willing to leave the street open for two-way traffic, especially in light of the fact that the natural history of disease and the health-impacts of Amish social practice have truly influenced patient outcomes in the past. In an interview, Dr. Morton pointed out that time, patience, and continuity provide the space for patients to “teach that [physician] what medical problems they have.” This kind of dialogue builds loyalty and compliance; without such a venue, Amish families “often just get frustrated by the fact that the system doesn’t seem to accumulate knowledge about them” (Morton).

The two-year shift a family must endure in taking care of a GA1 child under the protocols of CSC also requires a significant investment in the spiritual practice of patience. Visiting, interviewing, and observing the families in this young cohort of GA1 babies made it abundantly clear that these mothers were under a great deal of stress.

The psychology of having a sick child is one of intense fear. Of having a chronically sick child. And that, in a sense, is an opportunity because when you have a newborn baby and they have this Glutaric Aciduria, when you look around you in your community and see all these kids in wheelchairs with Glutaric Aciduria—and you will listen.

... When I meet with those families the first time of GA1, and I go through regimen, I spend, I usually, first visit or two, I spend three hours. I get out pictures of the brain, simple pictures, I have models, you know I have brain models and sit down with them and, um, if you do that, if you take the time and you stay in touch with them and you educate them, they buy into it.

Because in that crucible of fear, you throw them a lifeline, you say ‘Look there’s a way out of this, and there is a real way out of this.’ (Kevin Strauss)

Amish families, and mothers in particular, are asked to adjust childrearing practices and day-to-day lifestyles while putting some level of trust in the promise that CSC’s biomedical approach may save a child from a lifetime of profound disability. Like a myriad other examples in Amish worlds of practice, word-of-mouth testimonials about CSC and its success stories have gradually

earned it an irrefutable reputation of keeping GA1 kids healthy. Not unlike trying a new herbal treatment or water filtration system because your sister-in-law's uncle is sure it cured his cancer, CSC benefits from the rapidly moving inner news system among and between Amish communities. People have known GA1 kids in wheelchairs. People still know GA1 adults who have lived their entire lives with the brain injury. People also see this new generation of GA1 kids now running around healthy as their unaffected siblings. When a new baby receives a positive newborn screen, it's a rare family that would choose to risk the former. But going for treatment at CSC requires pulling on that well of patience and leaning on the expectations in Amish time.

One of the most significant impacts on that day-to-day practice involves the necessity of keeping these children well. GA1 babies and toddlers need to be kept from standard pediatric illnesses as much as possible, requiring a near quarantine state for the baby and its primary caregiver. In truth, biomedicine is not just asking Amish families to comply with technological and/or pharmaceutical standards but to actually shoulder the individualized nature of the autonomous patient in entirely saturating ways. Their community eschews this kind of individualism, placing primacy on the group, and operates at the level of practice within intensely active social spheres of face-to-face interaction. Home church, frequent visits, community-based schooling, generalized allomothering, work assistance, formal events, singings, the Youngie, mud sales, women's gatherings, wedding seasons, harvest/planting help, and the list could go on. Activities in Amish cultural worlds typically revolve around high-density interaction. Amish mothers with GA1 babies must virtually remove themselves from this dynamic as well as keep the flow of others away from their home in general for two years. And Amish mothers must also be willing to participate fully in a biomedical system that may feel

foreign or even unacceptable. Making this difficulty even more intense, many women are also managing a husband and multiple other children coming in daily from school and carrying the community's pathogens with them everywhere they go. Mary Wittmer put it this way:

All the children are, everything looks like a big germ! A big sickness coming in the door at me! Coming in from school, and like, oooo—'go wash and change your clothes!' Yeah, sometimes I probably overreact and the children get kind of upset about it.

An Amish mother must also be willing to give up the culturally-standard ways of caring for her infant—no nursing and switch to using the formula full time or be willing to endure a grueling pumping schedule to provide breast milk to mix with the formula. Mary talked about getting used to using an alarm clock for feeding Hannah in the middle of the night. Some nights she was so worried about missing the feeding, she couldn't fall asleep. And the few times she was so exhausted and slept through the alarm, she shot out of bed and gently agitated Hannah awake to see if she was still moving. But Mary was glad when Dr. Strauss urged her to get a babysitter and attend church occasionally or take part in other events. She thought at first that this was out of the question and his reassurance was a huge encouragement for her.

The difference between the stress outwardly demonstrated by the Amish and English mothers¹⁸³ in the cohort of patients was stark. Dr. Strauss noted that they "don't ever see compliance issues with English patients," but that the mothers are "distinctively more freaked out, all of the time." When one English mother arrives for a regular visit with her 1 year old, she stays in the car with him until an exam room is ready because the waiting room likely harbors far too many germs. She insists that the nurses swab down the exam room for her entrance but refuses to let her baby leave her lap or touch anything whatsoever in the room once she's arrived. The baby seems used to it, perched on her lap in a custom helmet to protect his skull incase of a

¹⁸³ There were two English families with GA1 babies that were coming in from out of state for treatment at CSC included in this cohort of patients under 24 months.

fall. She explains that there is no crawling around at home either and they're considering pulling their older kids from school until the baby reaches two. During every visit I observed with English mothers, Dr. Strauss expressed significant concern for (the mother's) mental health. "Your well-being, your family, your marriage, all the things that are important to you? You have to start to regain some normalcy in your own lives. Go to a restaurant," he suggests. This mother responds with a shocked gasp, looking insulted. "No, no, no way," she responds.

This disparity between the Amish and English mothers is clear when Mary Wittmer talks about meeting one of the English GA1 moms. Their two children are just a few months apart in age.

I really, really pitied her. I mean, she was scared. I mean, she had no body to talk to, you know. Here this baby was and she was supposed to keep it at home and nobody could really understand why she was acting like that with her baby. And you know, I still feel like I'm understood from my church, even if they didn't know what it was, they still respected us and didn't come [to visit the newborn].

... Even if I'm in [hospital] and there's an Amish family in here, you just go talk to them automatically. Even if you don't know them. You just cling to them, you just attract if you see someone standing there, you go talk to them. I am sure we have no idea how nice that is or the support we actually have.

The evidence in this chapter illustrates the many ways CSC makes that participation significantly more palpable for the *Gmay* and individual families alike. But Amish mothers are still left holding that syringe of Tylenol and deciding to feed it to their baby. Mothers are still left calling Dr. Strauss in the middle of the night to hospitalize their febrile infant for what would otherwise be considered harmless teething. This takes patience. And despite the incongruities of participating in GA1 protocols, Amish time and Amish community offers some sort of protection.

Lab and Clinic Integration and Small Scale Genomics

When Mary and Hannah Wittmer came into the clinic for her cold and fever, the visit

started with a blood draw and ended with Dr. Strauss's adjusting Hannah's treatment plan according to the lab report and all of the data he observed that afternoon. These young GA1 babies visit CSC monthly to check in and have their plans adjusted for growth, protein needs, and other nutritional changes. Typically, plasma amino acids are measured. Nurse Christine comes in the room, adeptly draws a blood sample, and walks that sample a few feet down the hall to CSC's lab. It takes about an hour from needle prick to an issued report. Nutritional counseling begins as plans for protein intake and formula levels are adjusted in real-time reflection of the body's current state. If Hannah was seen at a university hospital, physicians may or may not be familiar with CSC's novel protocols for treating her condition—the only place in the world where GA1 children are escaping brain injury at these rates. Even if they were familiar, elements of her treatment would be near impossible to replicate. Just getting Hannah's amino acids processed would take about 4-5 days, removing the possibility of on-site nutritional counseling to adjust the diet.

This is one small way the presence of the lab at the Clinic for Special Children refigures the network of biomedical practice in action. A dedicated lab certainly grew out of Morton's country doctor vigilance. Not unlike the Amish, he was going to do it *his way* in those early years. As a fellow, he experienced first hand the results of a bogged down laboratory model mired in systemic reporting vacuities. As the clinic continued to grow and it became more and more apparent that genetic disorders were presenting “to generalists as common problems such as failure to thrive, cerebral palsy, epilepsy, anemia, and sepsis,” (Strauss et al. 2012:e2) Morton and Strauss decided to keep the laboratory work in-house and expand the functionality of the lab

in pace with new technological advances in human genomics. In 1998 they hired a geneticist, Dr. Eric Puffenberger, PhD, to head it up¹⁸⁴.

The potential for integrating lab science with clinical work made this an innovative move, thus shifting the agency of the lab from an ancillary apparatus to a cohesive element of public outreach, healthcare, and health intervention. The integration of a powerful, cutting edge lab modifies the clinical model in two important ways that contribute to the ongoing relationship between advanced biomedical technology and Amish communities of practice. The first is the deliberate counteraction of the silo effect as biomedical cultures turn to increasing specialization. In virtually any other biomedical healthcare setting, a patient like Hannah Wittmer would likely be seen by an array of specialists separately or perhaps working in tandem. Depending on the services available to her, any of the following could potentially consult on her case: a pediatrician, an endocrinologist, a neurologist, a medical geneticist, a genetic counselor, a nutritionist, a molecular pathologist, laboratory fellows, and countless nurses. Her “team” could be vast and frequently shifting as residents and fellows rotate in and out of her case. And any research done with her information would be split out into separate projects with overarching aims that need her as a de-identified data point.

Reducing this mechanism and scaling down clinical genomics requires finding a place for disciplinary holism in biomedical cultures. It’s notable that CSC’s physicians toe lines between multiple medical specialties, subspecialties, and counseling positions¹⁸⁵. It is exceedingly rare,

¹⁸⁴ In an interesting turn of historic continuity, Puffenberger had worked as an editorial assistant on the Mendelian Inheritance in Man in the late 80s and early 90s.

¹⁸⁵ So notable, in fact, that it can be (and has been) very difficult to find young doctors willing and able to take on this kind of intellectual, physical, and medical challenge. After Dr. Rider left in 2011, finding a new physician was a long haul. Similarly, a large Amish group in Indiana has raised the money to get a similar clinic off the ground in their own community but the biggest stumbling block as been finding a young physician willing to step outside of disciplinary, research, and clinical norms to work with underserved Amish and their genetic conditions.

however, that the lab works not just to test and confirm values for patients at the Clinic, but to perform integrated research based on the DNA that walks through their door.

Even though something may be just technology that is brand new or hardly used anywhere else, it's used in a way here that makes sense and directly benefits patients and families. And I think that's really part of the key to what we're doing. We're not using the technology because it's interesting and fun to use and may someday benefit someone. It has a direct immediate application to those who need it. And that's very different. And that's why NIH doesn't fund us ... because everything we do here is driven by the needs of the patient who walks through the door and the use of equipment, technology, the development of all of the lab techniques that are so innovative here, are all based on children who walk through the door. (Caroline Morton)

In virtually all research settings, an investigator or group will create a delimited project and apply for funding to carry out the aims of that proposal. It is a top-down process. Working as a non-profit and taking no research funds from those kinds of agencies frees CSC to study the variations among the children that come to them. Subsequently, they make direct discoveries in human genetics and route those discoveries directly back into clinical care for their patients¹⁸⁶. This holism echoes the laminated identity in Amish cultural worlds and that echo bounces off of the history of medical research among the Amish. The symbolic, structural, and economic walls between clinic and lab are torn down at CSC to make room for a layered whole—a medical home. Even as far back as 1994, Holmes Morton was regularly presenting this idea as a key innovation in treating the Amish (*italics in the original*):

Control of specialty services and goals of research at times take precedent over the general healthcare and quality of life of the children with genetic-metabolic disorders. Research too often emphasizes use of university services and new technology over practical questions about daily care. I know that studies of the genetic disease of the Amish and Mennonite people have provided important knowledge, but I also know that some of the work with the Amish and Mennonite people of Lancaster County, done by teams of people from universities, has amounted to little more than *medical tourism*. Too often these teams of physicians, students, and blood drawers were disinterested in the

¹⁸⁶ Parents at CSC typically do sign a generalized consent form that allows the clinic to perform research with their child's information, to store that data, and to bank specimens on site. Because these studies are so amorphous and context-dependent, the consent process is remarkably open and short. This consent and other questions of human participation are overseen by the IRB at Lancaster General Hospital.

health care needs of those whose genetic diseases were studied. This is a harsh judgment, but it is true, and the Plain people know this. (Morton 1994:787)

The deliberate integration of disease knowledge, genetic information, and community history has created a space where it has become necessary to thoroughly integrate general pediatrics with genetic science. The continuity of care this generates provides for a cumulative knowledge that is unavailable at tertiary and academic care centers. This effort has resulted in the development of many of successful histories where direct molecular diagnosis leads to intense patient education, early intervention, and novel treatment protocols—as is the case with the history of GA1 in the Lancaster area.

Returning to the Amish pull toward craft practice and tactile work brings us to the second way that an integrated lab impacts the clinical model and contributes to the ongoing relationship between biomedical and Amish cultural worlds. Earlier, I discussed the built environment at CSC—more than built, but crafted in contrast to familiar clinical settings—and this divergence carries well into the laboratory. Windows across the front of the lab are mere feet away from the neighboring cornfield. Just past coat hooks open for straw hats or winter bonnets, the lab opens up off of the main hall of the clinic and sits directly across from two of the four exam rooms. Whirring of computer fans and centrifuges may play in duos with the jangle of horse-tack as a team treads by the windows while turning in the soil after harvest or hitching in the parking lot. After Hannah’s screaming fit from her “gix,” Mary Wittmer turns to me and says, “You know where they take that blood, they take it right there—(pointing across the hall)—it’s the workshop of this whole place. Those in there are the workers. That whole outfit is the workshop, right here in this place.”

The lab is visually and spatially available to Amish families coming through the clinic. That’s not to say they come, sit down at a lab bench and start messing around with vials. But

they can see the work going on as they pass by, they can walk in if they wish to say hello or even ask a question, they can survey the equipment and busy labor of Puffenberger and his assistant, Adam Heaps. These patient families have the ability to peek far enough into the black box of molecular genetics to get a picture of the tactile work involved in decoding bodily mysteries. But patient-family interviews rarely contained mention of CSC's lab in conjunction with ideas of cutting-edge science, despite the fact that the Lancaster Amish are some of the first communities worldwide receiving regular molecular diagnosis and genetically-tailored treatment plans for some of their disorders. Screenings and diagnoses performed there are regarded as pioneering; considered such a harbinger of a medical future based in new genetic understandings, the *New York Times* has called it "a model and a test of medicine as it eventually will be" (Belkin 2005).

They see the labor being performed before them; a product gets constructed at a (work)bench by human hands. Granted, those human hands are operating state of the art sequencing machines, pipettes, gene chips, filter papers, robust computers, and the like. But approaching their relationship to medical technology as "Amish" versus "high-tech" misses the point completely. While all of the Amish patient-families at the clinic demonstrated little appreciation for the advanced technology used at CSC in interviews, most associated the lab with the "work of doing medicine" or "the dirty part of the job." The lab was referred to in metaphorical language including: "where they stitch all the pieces together and look at what you've got going" and "the machine shop where they get it all going right!" The lab becomes another signal in the communal conversation around medical technology—spoken or not—where incorporating something like whole exome sequencing becomes acceptable because it is crafted, useful, tactile, and fully integrated into the clinical culture at CSC.

Economies of Care

In the work of any ethnographer, themes always arise during fieldwork that were not predicted when the project was conceived. In this work, that theme was money. Cost, economics, and money are a major driving factor and an essential feature in decision-making within a group that carries no medical assistance other than the aid provided by the church body as a whole. Using coded interviews from Amish adults, I found that two common patterns around money were consistent. In the majority of interviews, the participant would go through any number of moral or holistic reasons for choosing certain modalities or practitioners. Then, the participant would culminate that litany with money as the overriding factor. In the other scenario, interview participants would immediately identify money as the primary concern when choosing what strands from the plural system to utilize and then qualify that assertion with a number of moral, naturalistic, or holistic sub-reasons. In either structure, mentions of money were put on par with valuing God's knowledge over man's and these two categories were found next to modifiers like "the most important," or "really what matters." When asked what she thought the primary reason Amish tend not to utilize biomedicine, one Amish woman gave a typical response: "I think it's mostly financial. Because basically, if you really ask people, that's often what it comes out to being the real reason. They're scared to start because they could end up \$100,000 in debt and have idea how to pay it off." None of this is to imply that Lancaster Amish are either cheap or poor; many of them are neither. The second most common contextual modifiers after the ones mentioned above when discussing issues of cost were phrases about good stewardship of financial resources, frugality, sensibility, simplicity, and independence from worldly or state systems. Holding together as a community of practice in the spirit of mutual separation calls on that "we'll do this our way," attitude, even when it comes to paying a large hospital bill.

Lancaster Amish pay all of their health-care costs out of pocket, they carry no health insurance, and they do not utilize any state or federal aid programs. The community pays for what cannot be easily dispensed of on a family basis when larger bills are paid by the district's Amish Aid program. Like other aspects of Amish practice, this does not mean that there is a hierarchical decision model, a board of elders or bishops sitting around and deciding if Grandpa Amos gets his surgery or little baby John gets his new medication¹⁸⁷. The body politic of the Amish *Gmay* regulates those kinds of decisions. And this profoundly affects how families and individuals, as they conceptualize themselves as members of this laminated whole, think about their drain on the community resources. Kevin Strauss frames this well in an anecdote—one of many similar stories found in interviews, observation notes, and conversations about patients and finances around CSC. Strauss talks about a father, Abe, with multiple children seen at the clinic, all of whom are in wheelchairs. That family is not particularly well off; Abe works as a laborer and brings home around \$270 a week.

[H]e, he can't buy the right formula for one of his kids because it would cost more than his whole paycheck.

But the thing is that Abe knows he'll never really become completely bankrupt, there will always be and always has been people in his community that come help. On the other hand, he feels very guilty about that. And that's the, that's the interesting problem that a lot of people don't appreciate about these cultures is that ... the safety net from the community has a price, and the price is that if you're an individual who has to draw on that safety net disproportionately from your other community members, that carries with it a tremendous sense of guilt.

These families with kids with chronic diseases, they feel that. They don't want to have to tell their deacon that they have to put their kid in the hospital again. They don't want to tell them that there's a treatment that could save this child's life but it's going to cost them 15,000 dollars a month for 2 years. The deacon's role in most cases find ways to

¹⁸⁷ Kevin Strauss recalls a handful of incidences where this kind of thing has happened—where the church has made decisions about whether or not a medical procedure or treatment protocol suitable and a child may have been left untreated because of financial burdens. These types of cases would be rare outliers.

pay for that, but the parents really feel that they, they really feel the drain that it puts on the community, and they feel guilty about it.

The Clinic for Special Children has long been dedicated to addressing the multiple issues of Amish participation in high-cost biomedical care for chronically ill children. The economics of care were and have been major features in modifying a clinical environment in ways that favor Amish participation and continuity. Instead of finding ways to squeeze their patient population into standard models of compensation for care, CSC built and adjusted their system and operating budget to create an environment that encourages long-term cooperation with Amish church districts while making the pay structure culturally meaningful. They run as a non-profit and use no form of collections; families are trusted to pay their bills¹⁸⁸. Over 95% of their patients do not carry insurance because they are members of Plain communities; CSC, in turn, files no insurance claims, excises the administrative power needed to process insurance from their costs, and eliminates fee systems and coding inherent in dealing with insurance companies.

Mirroring Amish separation from the state and refusal to take up state-provided health money, CSC accepts no funds from federal or state agencies for clinical services or research projects. Economists, accountants, or policy analysts made none of these decisions. The doctors at CSC think about money because they have to. To keep kids in this self-pay community cared for and sometimes to keep them healthy at all, money must constantly be part of the conversation. To keep parents walking in the door when those parents have an array of more familiar health care approaches to try, money must constantly be part of the conversation. Other than these general elements of compensation for care, there are two large areas where CSC adjusts

¹⁸⁸ The vast majority of bills are paid at CSC; they have a very low rate of unpaid debts. Caroline Morton explains that CSC does no collection activity at all: “When it comes down to it, if the family can’t pay us, they can’t pay us and as a non-profit, you know, that’s going happen, we expect that. . . .but over the years there have been very few families who have not paid us. And most families pay us eventually. Sometimes it takes them awhile.”

techniques of economy in order to encourage and retain Amish participation. First, they push a model that focuses on the prevention of disease as the best way to reduce costs for the entire Amish community. Second, they've come to depend on the communities they treat to provide a large percentage of their operating costs via fundraising auctions as a way to maintain reciprocating relationships.

Becoming intensely familiar with the natural history of these diseases within these demes has made CSC able to narrow their inquiries significantly and save the community as a whole a great deal of money. They have learned both the cultural and economic significances of sparing many of their patients from the kinds of extensive testing those families have encountered at tertiary care centers. "Before the clinic was here, these kids would go through these diagnostic voyages at Hershey or Johns Hopkins, CHOP¹⁸⁹, and spend fifty, seventy-five thousand dollars. Sometimes they would get an answer and sometimes they wouldn't—most of the time they didn't" (Holmes Morton). In 2010, The Clinic for Special Children spent \$1.5 million to keep their clinic running, perform research, and care for 1877 patients. This number includes molecular testing for just over 100 pathogenic alleles. Their budgetary costs for that year break down to \$799 per patient. "By comparison, 2010 medical spending for the US population was \$8344 per person, half of which was paid by state and federal governments and the remainder split about equally between patients and private insurers" (Strauss et al. 2012:e3). These figures alone say a great deal about the cost differential in action in CSC's clinical model, and many of these cases are extremely complicated, chronically ill children.

Patient families I spoke with were well aware that CSC costs them less than other venues of biomedical care and saves money for the entire community. But few were able to express

¹⁸⁹ Children's Hospital of Philadelphia

exactly why that occurs. Some respondents cited the on-site lab as a money saving mechanism and many fell back on explanations like, “they just understand what we can pay for,” or “they care about the community and don’t charge all those extra monies,” and even “have you seen that little car Dr. Strauss drives? We’re not paying for cars like you do at most doctors. They just charge us what’s fair, not to buy themselves things. But have you seen that car? Maybe we *should* pay for one!”

Economies of Prevention

The integration of lab and clinic is indeed a major money-saving factor, as evidenced in the section above. Another large contributor to avoiding high costs is the benefit of staying small and working with the population genetics of a small community. When a molecular analyst reviews sequencing data, he or she must either sort through impossible amounts of information with a poor understanding of where to look (analyzing whole exome or whole genome data—needle in a haystack) or must first know how to limit that data in order to make the search more meaningful (targeted testing or use of diagnostic lists in large sequencing). At this point in time, one cannot simply sequence the DNA of a person and pluck out a disease-causing variant like a sore thumb. This kind of molecular reconnaissance requires a great deal of comparative knowledge about the individual. In many large studies, GWAS research¹⁹⁰, or investigations of undifferentiated populations, that comparative knowledge is wide and ambiguous. It often means comparing an individual to a number of reference genomes available in the literature; those reference genomes may or may not be helpful in terms of long-term evolutionary impact in this particular patient. Molecular analysis is a comparative science and the more verified genetic

¹⁹⁰ Genome Wide Association Studies

information one has at one's fingertips, the more robust that science grows. This progress is happening all the time, worldwide, but the information we currently understand about every potential deleterious variant in the human genome is enormously limited. The result is more of a goose chase—how do we pin these symptoms and phenotype to a molecular cause, how do we narrow our search enough to actually locate that molecular cause, and if we find it, how can we best confirm it or determine its medical actionability or a person's treatment options? Each one of these steps incurs cost, labor, manpower, and expertise. Meanwhile, a patient may be getting sicker and incurring additional treatment costs just to address the manifestations of their genetic variants. The Clinic for Special Children and its patient populations benefit from the cost savings inherent in staying small. This kind of genomic “scale down” serves as an antithesis to most genetic research going on today.

Being thoroughly familiar with the ancestral pools of your patient equates to having a large number of the mysteries already answered for you by virtue of compounded knowledge on that population. The Clinic for Special Children has spent over two decades building that genomic knowledge base and exploits it to make new diagnoses all the time. They know what they are looking for in testing for the Lancaster Amish variant of GA1, so they go right to that single change on the GCDH gene. More interestingly, when a child shows up with an unknown disease, the process of searching that child's DNA for a meaningful variant is exponentially easier than it would be if that child showed up with the same symptoms at CHOP or Hopkins. There, the child may endure unnecessary physical testing and poorly targeted genetic testing that may or may not hit on the etiology or molecular cause. Thousands of dollars in bills may accrue.

The coding libraries and institutional knowledge at CSC mean that Dr. Strauss can find out some basic information like surname or county where the child lives and take a quick look at

the phenotype of the patient to automatically rule out large swaths of medical possibility. If an Amish child with the last name Peachy comes in from Mifflin County, he might take one look at that child, remember three others with a similar phenotype in the clinic's history, and immediately locate the problem using \$50 targeted gene test. They would have their answer back from across the hall in 24-48 hours and he could contact the family with the news and start treatment immediately. If that same child showed up at a tertiary care center run by a university, the physician on the case would start with a much wider and more expensive array of testing. Even if that physician suspected a gene enough to order a targeted-test, that test alone would cost \$225 and have a turn-around of about 21 days. But let's say Dr. Strauss does not have a hunch or recognize something from the child's phenotype. If he decides to get whole exome sequencing data on the child, he's going to end up with tens of thousands of variants; knowing the child is Amish from Mifflin county allows Dr. Strauss and Dr. Puffenberger to radically pare that list down by comparing it to their control data from the same population. They've just subtracted out nearly all of the variation from the background and are likely left with just a small handful of variants to seriously consider. This is going to cost them an average of \$35 per exon with a turnaround of about 5 days compared to \$148 at the university lab and a wait of about a month. When multiplied by whole patient populations, these kinds of savings are huge. CSC does about 405 targeted variant analyses per year. Comparing their costs to the average costs at commercial and university labs shows an annual savings of \$144,788—that is just for one kind of test that focuses on targeted gene areas. Adding up this kind of annual savings for *all* of the large categories of testing performed in-house at CSC saves the clinic and its patient populations \$913,078 yearly as well as over 16,000 “saved days” of time spent processing, interpreting, or

waiting for results¹⁹¹. Not only is CSC able to get closer to the problems of their populations because of their accrued knowledge on these Plain communities, they are able to do it cheaper by running almost all tests in house. To say it another way, CSC is able to create more refined aims, test less, find out more, and all for less money.

As we've seen above, being a patient at CSC does not keep kids out of hospitals. With conditions like GA1, MSUD, and others, some hospitalization is necessary and part of the process in keeping these children well. In addition to all of the cost-conscious work they do at CSC, Kevin Strauss has made it part of his personal mission to advocate for Amish patients financial liabilities at local and regional hospitals. For example, he and Caroline Morton helped set up a charity fund at Lancaster General Hospital that defrays bills for Amish families needing frequent and high-cost hospital care. He has also lobbied regional medical centers to reduce cash-pay fees to Medicaid rate equivalents with good success.

While in the critical ages between 0-24 months, GA1 babies visit the clinic monthly. This frequency allows Dr. Strauss to keep pace with their growth at ages when their protein needs are constantly changing. At these visits, plasma amino acids are drawn, compared to control panels, and used to inform shifts in the baby's treatment plan. This kind of amino acid analysis at a university lab averages \$240 with a turn around of 4 days. It costs the clinic \$75 and the result is back in 45 minutes. This saves the Amish parents, and by extension, their entire church district close to \$4000 in amino acid screening *alone* over the first 2 years for one baby—to say nothing of the array of other costs. Between GA1 and an array of other conditions, the Clinic performs 1,310 amino acid analyses annually, saving Plain communities \$517,450 (Strauss et al. 2012:e3). If preventing GA1 injuries from occurring in the first place can be considered an “ah-ha!”

¹⁹¹ All of these testing costs and comparisons are taken from (Strauss et al. 2012:e3).

moment in the history of it's shifting phenotype in the Lancaster area, that same pull toward prevention can be recognized as one of the most cost-saving benefits for any family and *Gmay* with GA1 children. Even though these kids require frequent care in the first 24 months, it costs significantly less to prevent and manage an uninjured child than it does to provide comprehensive care for an injured child and adult with multiple disabilities. Strauss and his co-authors put it this way:

Few have attempted to place a dollar value on this type of strategy, but in 2004, the Centers for Disease Control and Prevention estimated lifetime costs, including costs attributable to medical care, assistive devices, transportation, special education, and lost productivity of disabled individuals and their caregivers, associated with the diagnoses of mental retardation, cerebral palsy, hearing loss, and visual impairment. Adjusted for a 6.1% medical inflation rate, they ranged from \$630,000 (hearing loss) to \$1,530,000 (mental retardation) per lifetime. These estimates indicate that preventing major neurological disability in approximately 200 children over the clinic's 20-year history has spared the Plain communities about \$270 million in associated costs. The clinic's cumulative operating cost over this same period was \$18.3 million. (Strauss et al. 2012:e7)

Just about one-third of that yearly budget comes from individual or philanthropic foundations, many of which are anonymous. Another third comes from patient fees paid in cash at the time of service or on a payment plan. The remainder of the budget comes from four annual quilt auctions organized and executed by Plan populations across the state. The largest of these happens every year in September at a produce auction facility in Leola, PA—about ten miles from Strasburg. In 2010, on the occasion of the Clinic's 20th anniversary, the Leola Auction raised \$310,000 in 9 hours “through the sale of donated quilts, furniture, homemade food, and farm goods” (Strauss et al. 2012:e3).

Economies of Quilts

A bright and sunny September morning greets us as the sun rises with not a single cloud

in the sky. Leola is a short drive up from where I'm staying but I wonder about stopping for breakfast anyway. I came down to the produce auction grounds last night with Dr. Strauss and the Mortons as they checked on everything getting set up. This produce auction site boasts a seven-acre auction facility combining small fields, an expansive paved area, and a string of open warehouse-style buildings in a line. The building sections are easily the size of a Super-Target and today it also boasts large white event tent set up with white-spined tops piercing the clear sky. It was an impressive sight empty, but that did little to prepare me for the massive influx of people and activity this morning. I turn down the road toward the auction area and find myself swamped by slow but moving influx of wagons, teams, bicycles, push-scooters, pedestrians, cars, and twelve passenger vans. Most of the cars are directed into a field on the left, across the street from the auction site. Just inside the gate is a patch of bicycles and scooters parked in messy rows—hundreds of them—and along the backstretch of asphalt stands a seemingly endless line of teams hitched in long rows, three teams deep. The carriages are mixed between Amish and Mennonite styles, as are the bicycles (Mennonite) and scooters (Amish). Young kids run underfoot every which direction, and the noise of a steam engine churning ice cream roars loudly in the background.

The Plain communities in the Lancaster area are decentralized and even totally unconnected in many ways. Any two groups of Plain Anabaptists may share a common history, common dogmatic practices, and similar materiality, but they exist in entirely different social realms and cultural worlds. However (dis)similar they are, it is not hard to drive into many areas of Lancaster County and be in public spaces with large numbers of Plain people in clear proximity to one another and the English. Mud sales or firehouse fundraising dinners also tend to have large swells of Plain attendees (or organizers). But the annual Clinic for Special Children

auction in Leola stands as one of the few public events that places an English person in the position of crossing a threshold between majority and minority. There are thousands of people here and the majority of them are wearing Plain clothes of one type or another. But the making strange cuts at many levels here. The auction also gives Amish a chance to commune widely with Amish from literally all over the settlement. No census is taken, but it is fair to assume that virtually every *Gmay* is represented here as well as Amish districts from all over the state. And the Amish eat, work, play, buy, and donate here alongside Mennonites from a wide range of church types.

It's a good thing I didn't eat breakfast. The first building and its adjacent tents contain food items for sale—foods being prepared hot for eating here (from omelet and pancake breakfasts, to pork sandwich and bbq chicken lunches, and every possible doughnut in-between) as well as foods to buy and take home (loaves of bread, jars of jam, and fresh whoopee pies by the box). For weeks, Amish friends have been telling me where they'll be at the auction. "Look for me- we'll be doing omelets." "I'm sure I'll be back with the pies most of the day, come by and say hi." "We do the powdered doughnuts, there's a group of us childless that take up the doughnuts." "My sister has a quilt in, so I'm going to sit at the main block until I see what it goes for!" Sure enough, I get a wave from a family behind one of the omelet griddles first thing and I go chat with them a bit; but the line is too long to wait for hot food so I grab a coffee, a giant sugar-encrusted bear claw type pastry, and keep moving.

Nearby, I register for a bidder's number and receive my yellow card; at the adjacent purchasing table, commemorative mugs are stacked for sale. Each year the mug features a different quilt motif and the year on one side with the CSC logo on the other. I make a mental note to buy a dozen for Christmas gifts. At the far end of this building was the first auction block

I come to. Amish church benches line rows out in front of the block for the bidders while the sides are 30 yards deep of handmade furniture. Beds, cabinets, chairs, shelves, in all styles and colors, tagged and ready to be bid on. A large wall of crate containers and tarps splits the open warehouse here and beyond that division the main quilt-block opens up, flanked on one side by 5 beautiful hanging quilts and racks holding the 78 large folded quilts tagged for bidding.

The stage itself is a litter of Amish-made toys, pillow tops, baby quilts, and commemorative pieces. A hand-written quilt list had been photocopied and placed in stacks on a table covered with wall-hanging sized pieces. Folding chairs in long rows face this main block. The area contains hundreds of seats, but the aisles and sides are constantly congested with spectators and traffic. Moving to the end of the same building are a third and fourth, smaller blocks for an array of toys, farm items, crafts, and other hand-goods. Outside, set up on the pavement is a small lot of yard furniture, playsets, and other large yard pieces that lead right into an out-building where farm implements, hand-built sheds, playhouses, and garages are being auctioned off as well. Many of the chicken coops and play houses, and yard sheds are set up along the pavement in a line with little swarms of kids playing in most of them. And at the tip of the yard, where the pavement meets the grass, a couple of fully-appointed buggies, flats of potted plants, a few small livestock, and potted trees are being auctioned off by a roving auctioneer with a wireless microphone. Groups gather around, six or seven people deep.

In an adjacent field, passels of young people gather in little cliques around a volleyball game with players rotating in and out. One minute the teams are six Amish boys versus six Team Mennonites and a group of forty chatty Mennonite girls sit along the fencerow giggling, gossiping, and pointing. A game or two later, a large swath of Mennonites cover the palettes stacked along the field side to watch six Mennonite girls get schooled by a pack of Amish girls.

The volleyball, intense teenage socializing, and general adolescent buffoonery across this multi-sect Plain group make it hard to tear myself away and return to the auction blocks. Amid all these stations, crowds of people shift around en masse like a giant swell of apron dresses and straw hats. The outdoor and patio furniture being auctioned are littered with people sitting, enjoying the sunshine, catching up, chatting. The playsets for sale are so choked with children that the spiral slides have clogged and a Mennonite teenager goes back and forth plucking giggling little bodies from the bottoms of the slides and shooing them up the ladders just to keep things moving. Baby strollers and wheelchairs buzz along, occasionally getting stalled in the traffic around the entrances to the main quilt block. It feels like a county fair, if every lady at your county fair had her hair covered with a *kapp*, kerchief, covering, or prayer square.

Some of these families are tied together by circle letters or *Die Botschaft* correspondence but only see one another at this auction every year. It's one part fundraiser, one part reunion, one part food-fest, and one part celebration of all the special children in the Plain communities. At 10:00am, CSC's doctors gather to address the crowd. They've each prepared a short speech. All of the auctions halt and a huge majority of the people in attendance floods the main block. The aisles and sides are blocked; people climb on pallets outside to get a view. Some men remove their hats to help a neighbor see. Each of the doctors gives a speech in turn, ending with Dr. Morton. The speeches are sweet, funny, heartfelt, thankful, and emotional. A stoic Amishman in the front row has silent tears rolling down his cheeks and disappearing into a lengthy white beard. Little kids sit criss-cross by the stage, craning their necks at these humbled doctors, listening to them talk about "preventing catastrophic disease," and "meaningful work," and how CSC would be nothing without all the people here in this giant warehouse.

\$310,000 in nine hours—nine hours to raise nearly a third of the Clinic for Special

Children's yearly operating budget. Every piece of that auction, every quilt scrap, every stick of furniture, every pie crumb, was donated by people from the Plain communities. And many of those individuals donating, attending, or buying goods that Saturday in Leola are *not* patients or directly involved in the clinic. Entire swaths of the Plain communities come to the Leola auction because they're investing in a biomedical practice that has invested in them. If CSC has kept one kid in a *Gmay* out of a wheelchair or kept one baby born with lethal microcephaly comfortable so he could die in peace, they have served the whole of group.

In these events, the materials of craft become social and economic currency in entirely different ways than they do during the day to day. Plain groups from all over the Lancaster area, all joined by their association with the clinic, come together for a day of food, auctions, and fellowship together. The main event, a quilt and craft auction, is supplemented by sales of just about anything made in Amish homes or shops. The atmosphere is joyous and carnivalesque, if carnival can be imagined in muted shades of blue and black. And all of the energy orbits around the agency of material craft. The futures of the clinic, the futures of Amish families impacted by genetic disorders, the futures of church districts working to maintain their separation from worldly concerns are all on the line and adeptly mediated by quilts and pie.

Conclusion

At the end of her book about the tragic "collision" of biomedical and Hmong cultures, Anne Fadiman considers:

... for better or for worse, Western medicine *is* one-sided. Doctors endure medical school and residency in order to acquire knowledge that their patients do not have. Until the culture of medicine changes, it would be asking a lot of them to consider, much less adopt, the notion that ... 'our view of reality is only a view, not reality itself.' (1998:276)

When this project began I was intrigued by the possibility of a biomedical setting where doctors

were indeed adopting an informed relativism toward both their patient populations and their own participation in biomedical cultural worlds. This was an assumption; my original impetus was to arrive in the field to ferret out the real areas of contention between CSC and the Amish community it serves. But contention was fleeting, if present at all. For a group of people stereotyped for dramatically removing those who can't conform under full social shunning, the Lancaster Amish are rarely antagonistic. This is not to say that without internal disagreement and external pressure. But it is simply not suitable to understand the Amish process of dealing with technological change and interchange with worldliness in terms of contention. It is not suitable primarily due to their central and sedimented reliance on *Gelassenheit*—the yielding, the giving up, the folding to the will. But what does it mean when members of a cultural world enact *uffgevva*, or “giving up,” in the spirit of *Gelassenheit* to create placidity and avoid situations of social inequity but still insist in interviews and observations that they do things “our way,” in acts of full separation from worldliness?

For one, these two communities do not totally valorize one another. It was not uncommon to hear editorial comments in interviews about preferring one Doctor over another, one saying Holmes Morton was entirely too difficult to understand while another claimed that Kevin Strauss just didn't explain things as well as Dr. Morton. Although not overly emphasized above, there were also moments when the staff at the clinic expressed frustration with or even dislike for the actions of some of their patients. Dr. Strauss told a few heartbreaking stories of families being torn between utilizing the clinic or staying with “natural” healing methods when one parent wanted something different from the other. There were times I was warned ahead of time before interviewing Amish individuals who were particularly harsh, difficult, or dismissing of English interlopers—and when I arrived at their homes, those warnings were fully warranted. The

language of “supernatural healing” was common when the physicians and nurses at CSC would talk about utilization of other health modalities with me or amongst themselves. From above— “[T]he specter of supernatural healing is still all around us, it’s a sea, we come in contact with families all the time, who have been treating things with poultices and charcoal and magnets” (Kevin Strauss). But this rarely came to bear in the form of continuous interaction between clinicians and patient families. The easy and obvious reason is savvy on the part of the clinician—a cultural acuity about Amish health pluralities on the part of the providers. Equally, Amish patient families seemed to only sometimes reveal the extent of their other, simultaneous treatment regimens.

But I saw the reason for this absence (of supernatural healing as a divisive factor between the communities and the clinic) as a reflection of the way Lancaster Amish conceptualize healing and the body. The Amish interviewed for this project did not attribute healing to supernatural powers or blame God for medical misfortune; these notions just did not line up with how Amish talked about using a naturopaths, chiropractors, herbalists, cranial-sacral therapists, or other health approaches. It may look like dependence on the supernatural from the outside, but underneath that veil, Amish in the Lancaster area are instead engaging in their own set of decision matrices around technology and health modalities. Explanatory models of healing allowed for a very heavy dose of providence and acceptance of a greater spiritual world affecting this one, but “supernatural healing” ended there. Instead, God’s knowledge provides individual bodies the power to heal themselves. Families were constantly balancing the knowledge dualism as a way to understand their own participation in the world of CSC. Many extended this to the staff at the clinic with God’s knowledge giving them the tools to become great doctors (thus trumping the knowledge of man implied by secular science). Scheper-Hughes and Lock refer to

the social body in terms of “the frequently encountered symbolic equations between conceptions of the healthy body and the healthy society, as well as the diseased body and the malfunctioning society” (1987:20). And this is what the Amish participating at CSC are largely doing—consistently falling back on notions of the social body girded by the knowledge of God as symbolized by the individual body. Further, by assigning the role of “special children” that serve to enhance Amish practices of humility, patience, stewardship, and community love, the potential for malfunctioning society as a reflection of diseased individuals is kept in check. Special children enhance Amish practice by bringing followers of faith closer to God. The Clinic for Special Children, in turn assists in that journey by improving the lives of those who suffer.

Medical anthropologists often look at sets of people who have been quite suddenly brought into relationships with new knowledge about illness and new medical technologies. Literature in medical anthropology emphasizes ways in which these technologies and scientific efforts presume and thus create self-conscious, autonomous subjects out of patients (Adams and Pigg 2005)—as disease is empirically approached as a set of symptoms and biochemical reactions that may be tweaked in the research setting and then applied *upon* patients. For much of that process, the patient is relegated to the role of recipient-machine; not only are lab and clinic structurally and economically separated, clinician and patient are often relegated to low-functioning relationships where bodies get reduced to complex but discoverable sets of machinery. This kind of relationship between practitioners, patients, and their own disease is not lost on the Amish. They’ve experienced it in hospitals and other clinics; they’ve heard about it from friends and in *Die Botschaft*. And this generates a real disconnect as the church districts in Lancaster foster a culture that purges individual expression to place primacy on the group. From the Amish approach, here we see the body itself becoming a space where the community guides

knowledge production and the negotiation of technology. This will be discussed in the next chapter. For now, it is important to point out that the Amish community around Lancaster has effectively pushed the possibility of community-guided knowledge production upon one small realm of biomedical culture—The Clinic for Special Children.

The critical eye of medical anthropology encourages its practitioners to be aware of our own positions as naturalized consumers of biomedical models, metaphors, ideals, structures, and materials. It also encourages us to be aware of hierarchies inherent in those models, including the power structures within clinical settings and potential for venerating physicians by virtue of their position or capital. Once again, the criticisms I was looking to make in this regard were weak when held up to the evidence. Take this statement from Scheper-Hughes and Lock in regards to the mindful body, biomedicine, and social science:

Biomedicine is still caught in the clutches of the Cartesian dichotomy and its related oppositions of nature and culture, natural and supernatural, real and unreal. ... Physicians are increasingly looking ... for the answers to the ultimate and persistent existential questions that are not reducible to biological or to material 'facts.' Why this person, of all people? Why this particular disease? Why this particular organ or system? Why this 'choice' of symptoms? Why now? (1986:30-31)

Do the physicians and researchers at CSC operate from a foundational reliance on the Cartesian dichotomy? Do they reduce bodies to sets of operable machinery? Yes and yes. But do they also ask questions like “why this person,” “why this particular disease,” and “why now?” Absolutely.

As they visit in their long appointment and wait for lab results to return, GA1 parents at CSC are educated directly on the importance of paying extremely close attention to regular pediatric complains (such as fever or ear infection) that can also trigger brain injury. As their social relationships with these doctors strengthen, their trust of the information received in visits increases; as a result, they have become some of the first Amish worldwide to utilize pharmaceutical fever reducers. This may not seem significant, but this detail is a major

contributing factor toward radically altering the outcomes of GA1 in Lancaster. The simple act of having Motrin available at home for an ailing infant has undeniably improved the injury rates in GA1 patients. It's been a slow process of mindfully evaluating, experiencing, and reevaluating technologies as a whole community—with that individual body of a special child sometimes standing in for the whole *Gmay*. Some of these technologies are complex—the molecular diagnosis via newborn screen of GA1 using PCR-based double-stranded automated sequencing (in the sense and antisense directions) for exons 1-11 of the GCDH gene, plus at least 20 bases into the 5' and 3' ends of all the introns. Some of these technologies seem more simple—the administration of Motrin to a baby with a fever.

Environments that modify gene expression and produce phenotypes arise from cultural worlds in practice. And patients are not just involved in *their* cultural worlds when they come swinging into *your* clinical ones. Recognizing and adjusting for this concept has been key to the success at CSC, and this has resulted in a shift in the ways both medicine and research gets conducted there. Talking about the impact of environments on gene expression and subsequent phenotype cannot be left to the environments patients live in outside of medical care itself. The staff and physicians at the Clinic for Special Children approach medicine with the perception that biomedical culture itself exists as part of the environment implicit in manifestations of disease and thereby shapes health outcomes and phenotypes.

Chapter 6: Sacrifice and Amish Embodiment

Introduction: Amish Bodies

The last three chapters have emphasized ways Lancaster Amish communities of practice build and participate in a pluralistic system of healthcare rooted in socially-informed bodies. The co-occurring structures of Amish social lives and the subjectivities formed in those lives affect how they negotiate illness, disease, healthcare, and social wellness. I have described ways in which the Amish “body” intercedes between the self and its community, among the community and the outside, and around the artifacts that populate its cultural world. And those bodies are deeply imbedded in what it means to be Amish—from the twisting double helix of a Lancaster Amish genotype (object/nature) to the implications of mutual separation on daily practice (subject/culture).

Mauss’s conceptualization of habitus attached cultural practice to the body (1935) by tying the techniques of embodiment and perception to the “work of collective and individual practical reason” (2001:53). But Mauss still avoided bridging the divide between his notion of the person and the techniques of the body with a “consistent paradigm of embodiment” (Csordas 1990:7). Bourdieu’s extension of habitus added bodily dispositions reacting to both perception and action, thus joining the objective social realms with the subjective experience of the self (2006), and he concentrated on individual consciousness as “socialized subjectivity” stemming from social forces (Bourdieu and Wacquant 1992). Csordas’ call for embodiment as a paradigm

in anthropology grounds practice in the socially informed body and provides a model by which Merleau-Ponty's preobjective and Bourdieu's habitus "guide analysis in the empirical domain of religious experience and practice." The analysis of perception and practice grounded in the body not only collapses subject/object dualities, it can open up investigations into how selves are constituted throughout the flux of cultural life (Csordas 1990:40).

In chapter four I put the coproduction of Amish phenotypes and genotypes in line with Lock's "local bodies" by invoking her definition wherein "the biological and the social are coproduced and dialectically reproduced" (2001:484) in contexts of Amish plural health fields. But I stopped short of the end of Lock's quote. She goes on to emphasize the individuality inherent in the cultural and material body:

The material body cannot stand, as has so often been the case, as an entity that is black-boxed and assumed to be universal, with so much sociocultural flotsam layered over it. ... The embodiment of the coproduction of local biologies and culture is, by definition, internalized and individualized. Humans are unique¹⁹² in terms of both their genetics and their lived experience, and to this extent, embodiment is personal (Lock 2001:484).

These embodied individuals are dynamic players in their cultural world as individual experiences around health and illness become symbolized in the social body (Scheper-Hughes and Lock 1987). But thinking about that locally—when applied as an analytic to the case of the Lancaster Amish—pushes right back against the rushing flow of individuality swept up by Amish mutual separation and refigured as collective group identity. Conceptualizing Amish cultural worlds as interpreting individual action in contexts of collectively produced horizons of meaning opens the way to collapsing subjective/objective dualities in the search for selves. In other words, framing theories of practice as rooted in socially informed, local bodies offers us the opportunity to look

¹⁹² Lock does account for "biological attributes common to a proportion of individuals who live in close proximity to one another and who have a reasonably close shared biological ancestry" (2001).

for the permeable boundaries between phenotypes and genotypes, between the knowledge of God and the knowledge of man, and between the concurrent existence as objects and subjects.

Earlier I said that in order to understand how social participation in cultural worlds shapes agency as individuals, we must first establish the bounds and influence of that cultural world and then look to how it bears upon personhood. I hope to this point, many aspects of the cultural world have been clarified. This chapter continues that description while picking up the second of these tasks in three ways. Amish mutual separation bears upon personhood through the experience of an Amish embodiment, through the use of a local body politic to regulate the cultural world, and through the self-sacrifice required in Amish baptism.

Amish Embodiment, Time, and Crafting Experience

Paying attention to craft and practice as a dialogic interchange allows us to combine explicit and tacit knowledges of work with the multiplicity of aesthetics and materiality. In this sense, crafts of carpentry, quilting, doctoring, parenting, networking, narrativizing, and others all point us back to enacting cultural worlds through local bodies. If embodiment is, at its core, tied to Bourdieu's habitus of the "socially informed body" denoted through sensory perception, then Amish embodiment is both a symptom and product of an aesthetic that gets continually implicated in the experiential temporality of "Amish time." Paul Lehman, an Amish construction worker from east-central Lancaster County explained that:

It is our own speed when we pick up new things. You have to do these things in the right time, you know? To every time there is a season. And it's not always the season ... You know its right when God makes it right for all of us or if pushing toward something, if somebody starts that up, well, we talk about it and make sense of it all before just all getting aboard the thing. Amish people, we make decisions this way—it's a season—we don't rush it but know when the season has come.

A good first step in grasping the Amish negotiation with the world requires conceptualizing their

cultural milieu as dictated by the sense of Amish time Paul refers to here. The English often assume two types of time when talking about the Amish: time as a measure of historical eras with their recognizable ephemera and time as a progression of ideas that build into an increasingly technological, convenient world. But reducing the Amish down to history, memory, and tradition does not do justice to their vibrant communities. Earlier, I discussed how theologically-central essences around patience greatly particularize the sense of Amish time and are subsequently used by the Clinic for Special Children as paths toward working together across cultural difference. Here, I pick up Amish time to explore how it shapes embodiment by altering the ways bodies move through space.

The sense of what it means to be Amish in Lancaster becomes sedimented in common situations of everyday life, affecting everything from expressed attitudes, to patterns of consumption, to decisions in healthcare. Some studies have accessed tacit aspects of experience in Amish bodies. Smucker (1988) demonstrated that private thoughts and language formation are greatly impacted by Amish cultural norms; for example, Amish children were far less likely to employ first person singular pronouns than their non-Amish counterparts. Gillespe (2010) solicited hand-drawn maps to demonstrate how the cultural boundaries of the *Gmay* manifest in children's cognitive interpretation of space. For example, in contrast to English children, Amish children minimized the existence of English neighbors by routinely leaving them off of spatial drawings and only including details from their own sense of community (Gillespe et al. 2010:26). The emphasis in this dissertation: mutual community alongside separation from worldliness informs these and other kinds of Amish subjectivities.

I like to joke that the Amish are terrible at giving directions, but the truth is that our spatial realities have been shaped quite differently over lifetimes of moving through the world at

different speeds and with different senses of time. For example, an English person might divide travel into distances appropriate by car or those necessitating an airplane while an Amish person might divide travel into distances that are appropriate by team and those that necessitate hiring a car. This is a simple and obvious example, but take a moment to think about the physicality, the process, and the spatial experiences that any one of these modes of travel implies. As an ethnographer, I was constantly taking down driving directions and attempting to find participants at their homes and on their farms. The first time I went out to Luke and Esther Schwartz's farm, these were the directions I received¹⁹³:

Gordonville? That's a ways off. Not so far as here [CSC], I suppose. So, come on out a bit on [the state highway] if you're coming from Gordonville. It's a ways back. Get yourself turned up toward Blue Ball. After a pace, turn left on Apple Lane to get going up the hill. The road narrows there just before the bridge but widens out again. You'll know you're going right when you hit Elderberry Street, you can't go but right and it bends around the Miller's old tree—it was hit by lightning last summer. Straight away again and you are closing in when you pass the old schoolhouse. The road gets really bumpy for a few minutes—that's when you know you're getting close, with the bumps shaking you around! Pass a blue barn right on the roadside, Sadie Martin's apple orchard there, and you'll see her sign for eggs. Our mailboxes are down on the road, turn in the lane there, but you'll probably hear the Martin's dogs barking before you see the numbers. Six-oh-six, that's the number, but you know the house is on down the lane.

I drove out to the Schwartz's place and got a little lost, finally giving up and mapping the route on my phone. Once I saw a digital version of the map, I realized my error. Like virtually every other time I'd gotten lost using Amish directions, I'd missed a turn or overshot a landmark—I was always going *too far*. The next morning, I decided to trace my steps up toward Luke and Esther's house once again in an attempt to figure out what I was missing.

Setting out that morning I thought the big problem would be twofold: subjective measures that were not helpful in determining actual travel details and simple descriptors that come from being familiar with the area and would not make sense to a visitor. These directions

¹⁹³ Street names have been changed.

contain both of these. I had to know where Blue Ball was to figure out which way to turn on the state highway. The “Miller’s old tree” that got struck by lightning looked, to me, just like a regular tree. I clearly had not known its previous splendor. The “old schoolhouse” was hard to see because it was quite far up a long lane and partially blocked by a hedgerow on one side of the schoolyard fence. All of these were simply not familiar to me as a stranger. Differential subjective measures like “a ways off,” “out a bit,” and “a pace” were dreadfully unclear when driving lost on bendy rural roads.

But there was something else about these directions and others I received from Amish families beyond my inexperience with the area or vague descriptors. The *Gmay* is defined by a close geography; families can always get to church with their team. Although one school may pull kids from multiple districts, school houses are frequent enough that most kids can walk or have a parent drop them off in the buggy¹⁹⁴. Some of life’s requirements require riding in a car—a construction job in the city, a trip to a distant supermarket, a doctor’s visit on the other side of the county, a visit to other family members. It’s not as though the Schwartz’s have never traveled this same route as passengers in a van taxi. But neither of them has ever driven a car, even as teenagers. The imprecision of the directions decreases rapidly once Luke is describing landmarks within a team-appropriate radius from their farm. The total trip was just over twelve miles but the first ten, which include a wide possibility of routes and multiple turns, was described as such: “... come on out a bit on [state highway] if you’re coming from Gordonville. It’s a ways back. Get yourself turned up toward Blue Ball. After a pace, turn left on Apple Lane ...” Once closer to the team-appropriate radius of their district and nearby neighbors, the detail swings much too far in the other direction. The last two miles are described with over a dozen

¹⁹⁴ While most children walk, there are rare arrangements where kids are bussed to and from school.

features or landmarks. Retracing my path toward Luke and Esther's made it clear that I was missing turns because I was looking for features that are either difficult to notice or imperceptible while traveling inside of a car at the speed limit.

In an effort to slow myself down and approximate the time it would take an Amish body to travel these two miles, I parked my car and took a push-scooter out of the back to try and identify some of what the Schwartz's perceive in the two miles leading up to their farm. By drastically slowing down the time and speed with which the world was experienced, most of the details in Luke Schwartz's directions came to life in tangible and sensory way.

...turn left on Apple Lane to get going up the hill. In the car this hill was not very noticeable, mostly because it was a short distance—maybe 25 yards—before I reached the bridge. On scooter, however, the incline was more real; it felt like cycling up a hill. *The road narrows there just before the bridge but widens out again.* I was too distracted thinking about missing the hill to notice the road narrowing, but this detail had me worried I was in the wrong place. Some bridges in the county do narrow to one lane and the covered bridges that are two tend to be narrow either way. This was neither. Scooting, however, I lost the shoulder. As it turns out, the road itself did not narrow but the shoulder disappeared. Teams tend to use wide shoulders as their own lane on very busy roads and on less-traveled roads, many buggy drivers will move onto the shoulder to allow cars to pass. *... you are closing in when you pass the old schoolhouse.* In the car, I totally missed it. What schoolhouse? By scooter, I catch a bit of the roofline behind a thick hedgerow and down a very long lane. As I move on, the small white building comes into view atop the crest of a small hill. *The road gets really bumpy for a few minutes—that's when you know you're getting close, with the bumps shaking you around!* In the car I feel no bumps whatsoever. Are these supposed to be speed bumps? Gravel? On the scooter I bounce over a

patch of bumps like rumble strips on the shoulder and look to see a matching set on the opposite side. *Pass a blue barn right on the roadside ... I can't miss the barn with a long blue expanse running along the road. But suddenly I've missed everything else and have to turn around in a lane with mailboxes marked 609-611. Sadie Martin's apple orchard there, and you'll see her sign for eggs. Our mailboxes are down on the road, turn in the lane there, but you'll probably hear the Martin's dogs barking before you see the numbers ...* None of these register in the car. And moving along on my scooter, I see why. The barn is on the left while Sadie Martin's outcropping of apple trees and egg sign are on the right, followed immediately by the Schwartz's lane marked 606-610. Just as I slow my scooter near the apple trees, I hear a pen of dogs yapping enthusiastically around the back of a carriage house.

I'd missed the Schwartz's house mostly because the speed at which I was traveling moved me through that space too quickly. Slowing down the amount of time it takes to pass from the state highway to the mailboxes marked 606 increases the body's ability to perceive a thicker material world—hills, bumps, buildings in the distance, dogs barking. The same can be said for using Amish cultural artifacts (approved technology) as scooters and buggies would expand your driving space to shoulders while exaggerating how the body absorbs topography. Luke's directions and countless others reflected all of these. This thickened environment demonstrates something tacit about Amish embodiment—actors moving through the world in the garb of Amish time and Amish materiality.

The Schwartz's experience the trip between their farm and Gordonville in entirely different ways than an English person typically does—a single horse, hitched to a buggy, creating no engine noise, utilizing road shoulders, and moving at an average five to eight miles per hour. Similar to how a bicyclist knows the back roads, sidelines, and paths that connect

neighborhoods in a different way than a motorist, the horse and buggy driver sees the world pass by at a slower speed and from a different vantage than his car-driving neighbors. I propose that this can be extended out as a metaphor for Amish embodiment in general. Dressed in the garb, performing the work, utilizing the cultural artifacts, and investing the in the spiritually-led *Gmay* all happen at a slower speed and from a different vantage point; this habituates bodies and embodies habitus. And so, it turns out that the Amish are not bad at giving directions. I was bad at translating those directions in terms of how bodies move through the world under a sense of Amish time.

“North Carolina,” Luke said when I arrived, pointing to my license plate. “How far away is that?” I was not so sure how to answer—would miles be most appropriate, or do distances fall into other categories? Many Lancaster Amish vacation in Florida, or are at least familiar with it, so I responded, “It’s about halfway south to Florida—about 8 hours in the car.” He nodded, and turning to the door to let me in he exclaimed, “That’s quite a pace, quite a pace!”

Chronos, ongoing time, is metered out in predictable intervals. *Kairos*, the opportune moment, comes in ephemeral but timeless bursts. In rhetoric, temporal choices are constantly being negotiated. The choice is not if to speak but when it should be said. *Kairos*, then, is understood as these moments of opportune action, it dictates that what will be spoken is done so at the right time (Poulakos 1983:39-41). Quantitative ideas of *chronos* certainly have importance in Amish communities of practice with such strong agrarian roots; many bodies move through the day at a pace metered by light, seasons, and the natural world. Even business people, like Paul Lehman, who no longer rely on milking cows at the same time every day, shape their daily lives in ways that mirror their agrarian past, and with little electricity in the home they remain bound to a schedule dictated by sunrise and sunset. But the deliberate negotiation with

technology slowly adjudicates not *if* to incorporate something but *when*—these are the moments of technological *kairos* in the temporal space of the Amish.

This is a type of modern-day realization of Agamben’s assertion that a Judeo-Christian messianism evidenced in Pauline writings entails *kairos* that enables the stretching out and suspending of *chronos*. This becomes the “opening through which we may seize hold of time, achieving our representation of time, making it end” (Agamben 2005:100). Agamben’s kairological suspension of temporalization, allows for a “mastery of chronological time” (Johnson 2007:266). Recognizing the Amish deliberation around their technological practices as *kairos*, they side-step increasing toward a chronological horizon in favor of the flexible moment. This is bolstered by their relegation of the *Ordnung* to the oral record, further removing them from coinciding with *chronos*.

Like the messianic presence, this removal from the “chronological instant” allows the moment to seize of this instant and bring it forth to fulfillment—both the now and the end of time (Agamben 2005:69-71). Mirrored by Amish theology, Agamben’s apostolic time is neither prophetic nor apocalyptic. Neither dwells on an end to come. Instead, the absolute present found in *kairos* as a solution to an infinitely divisible *chronos*, becomes the absolute future to come and thus as constitutive non-self-coincidence (Johnson 2007:276-277). As Paul Lehman says, we meet the seasons as they are revealed to us through the present moment. Amish time moves at a different click—not more slowly, but perhaps more deliberately, perhaps with more patience—and the season for drawing new practices or technologies into the community must be both opportune and appropriate. And that aptness typically hinges on the item or idea’s ability to bring moments of Amish mutual separation forth to fulfillment.

The Body Politic and Genetic Bodies

The second way Amish cultural worlds bear upon personhood comes through the *regulation* of that cultural world by the Amish body politic. Up to now, I've referenced Scheper-Hughes and Lock's frame of the overlapping "three bodies" in medical anthropology to discuss how "individual" bodily experiences are symbolized in and by the "social" body. Their frame continues with the "body politic," a move beyond collective representation of the natural and cultural toward thinking about power and regulation (1987:23). No matter the type of polity, the body politic regulates the social while disciplining the individual. Scheper-Hughes and Lock point out that considerable literature has been written about this kind of control in industrialized societies, citing Foucault's work as the best example. They go on to note that less literature analyzes how "preindustrial societies control their populations and institutionalize means for producing docile bodies and pliant minds in the service of some definition of the collective stability, health, and social well-being" (1987:8). For the Amish, of course, these institutionalized means are not put in place by ruling classes or a hierarchical leadership. Control and regulation are constantly enacted through the performed cultural world as a product of social behavior. Power resides in the dialogic shaping within communities. In this non-anarchist, headless, consensus-based society, the body politic exists as a feedback loop in the spaces created by Amish communities of practice. Through years of practice in these spaces and through key events in individual Amish life course, the Amish person thoroughly personifies and so reproduces Amish collective identity—he or she *embodies* what is to be Amish.

In that feedback loop there are specific mechanisms for reproducing and refining the laminated community of practice. Regulation first occurs, of course, in the formal maintenance of the *Ordnung* through twice-yearly review, maintained by the oral record, and placed in

conjunction with the open reconciliation of dispute or disagreement between community members that must occur in order to take Holy Communion. In those meetings, church members must openly reconcile with any other member should the two hold disagreements, slights, or injury between them. Communion is a collective act of community engagement¹⁹⁵ and cannot occur until the whole community of practice can “speak in one voice.” Once this harmony is reached, the group takes up the freshly reaffirmed or refurbished *Ordnung* to ratify all those elements that regulate their world of practice. Every church member has a vote and every vote must be heard.

Die was effentlich gsindeht hen, hen effentlich bekenne misse—those who sinned in public must confess in public. Should any member stray from the measures outlined in the *Ordnung* or violate biblical teachings, he or she must bring it before the whole *Gmay* in a special member’s meeting held after church services on a Sunday. The unbaptized are dismissed from the room. The call to submit to the *Gmay* may be voluntary on the part of the petitioner or come from the lay leadership of the church.

The severity of the act gets played out physically. Less serious offenses require a “sitting confession” where the offender is presented in a seated position, the Bishop explains the offense, and the offender asks the *Gmay* for forgiveness. More serious offenses require a “kneeling confession” where the offender is brought to his knees, possibly questioned by the Bishop in front of the members, made to tell the story of his infraction, and made to leave the room. The ministers have typically decided on a consequence for the infraction ahead of time and the *Gmay* is then asked to vote on placing that consequence upon the offender. In some cases, that

¹⁹⁵ This Anabaptist approach is quite different from many interpretations of the Holy Eucharist in the Christian tradition where the rite gets framed as a symbol meant to mediate “the grace of salvation” to the individual recipient (Yoder 1991:38). Just as Yoder emphasizes this (along with other Christian sacraments) as “illuminating social ethics,” (1991:40), communion among the Amish is reproduced as a reenactment of the biblical/Apostolic community of practice and thereby serves as a ritual marker in the maintenance and enactment of Amish cultural worlds.

consequence may be a temporary ban. The offender remains part of the community and other members visit him to encourage repentance, but he does not participate in community gatherings like church meals. He does, however, attend church, where the temporary suspension from the community of practice is also played out on the body—he must sit for these weeks in the center of the service by the ministers and posture himself bent over in supplication with his hand placed over his face¹⁹⁶.

Mir welle net, awwer mir misse ihn meide—we do not want to, but we must shun him. The most serious consequence of failure to reproduce the cultural world properly through upholding biblical teachings and the *Ordnung* is excommunication or *Bann*. Well known to the English is the accompanying *Meidung*, or social shunning, of the persons placed under *Bann*. Shunning runs a spectrum along Amish districts—the more conservative the district and affiliation, the more thorough the shunning will be (*streng Meidung*). The body politic acts to force amputation of a damaged/ing member from the community of practice in a direct reflection of the collective identity of that community and the cohesive social body. Excising a piece of that social body moves an individual from the inside where he is included, laminated, and nourished, to the outside where he may be excreted, amputated, or starved. The body politic regulates this excision in the spirit of helping the offender.

Rhetoric concerning Christian love runs through any discussion of *Meidung*—ex-Amish may have been amputated, but they were once part of the body and must thereby be treated in the spirit of religious love. Nonetheless, individual bodies should not come in physical contact for the sake of both parties. It would be, for example, an act of love to avoid handing an object directly to an ex-member—but even more so in the presence of the wider *Gmay*. Due to their

¹⁹⁶ For a detailed description of these disciplinary meetings and actions, see (Kraybill et al. 2013:92-96).

blunt excision, the shunned are sentenced to a life where they may be helped by the exponential power of a collective community but forbidden to help a community member in return. The *Meidung* is, at its core, a social act exercised by the whole community of practice. Kraybill et al. put it this way: “Because these are *group* rites of shaming—not acts of personal animosity—their importance swells in social settings” (2013:167). A less conservative family that may allow a shunned adult from the family, such as a grown child, to join them at the dinner table with a small physical separation (say a gap in the tables or a ribbon stretched across the tablecloth) would not acknowledge that person at a church dinner.¹⁹⁷

Another reason I want to bring regulation in now is to think about the body politic as a way for understanding the negotiations going on around healthcare utilization as decisions are balanced between the individual and the collective. In its work of regulatory momentum, the body politic gathers together all of the matters on the decision matrix discussed in Chapter 3: cost of care, continuity of care, appropriateness of care, word-of-mouth referrals, craft practice, perception of natural origins, and the knowledge dualism pairing the knowledge of God and the knowledge of man. Where a particular practitioner or healthcare modality may fall on these continuums are ultimately decisions about the social *and* individual body as well as the object *and* the subject. As we saw in the last chapter, the craft of biomedicine and patient-hood are places to investigate those continuums. The interactions and relationships built at the Clinic for Special Children offer us examples where experiential relationships must be understood as requiring, involving, or at least interacting with perception. Among the Amish, bodies encounter deep aesthetic experience owing to constant familiarity with and production of the body itself. This continues right through the clinic doors while negotiation of genetic technologies by the

¹⁹⁷ For a detailed description of shunning and excommunication, see (Kraybill et al. 2013: 164-68).

body politic serve to maintain subjective experience and its implications for the health of the social body.

There are many directions to go from there, but I'd like to look at Byron Good's suggestion that we challenge biological reductionism by approaching disease itself as an aesthetic object (1994). Using "aesthetic" as a category echoes my focus on craftedness— aesthetic as an unspoken and fluid set of principles that guide the work of cultural artifacts. Aesthetic is a *sense* of what is crafted, for whom, and by whose hands. Genetic disease can be cast in the same mold. GA1 has been built within Amish genotypes over the course of the last two-and-a-half centuries. It has also been built through Amish social interactions and through enacting practice in the cultural world. It is in the in-between this nature and culture that CSC attempts to intercede.

According to Good, disease harbors a multitude of significances—personal, social, political, medical—that are perceived and discovered bit by bit. Thinking of disease as an "aesthetic object is thus constituted in relation to the constraints and resistances inherent in reality, as well as local processes of meaning-making" (Good 1994). An Amish family may learn about GA1 from encounters with another family, from screening performed by a midwife, from a late night phone call from Dr. Holmes Morton, from discussions with physicians or staff at CSC, from circle letters or correspondence papers, and, of course, from primary embodied experience of having GA1 or caring for a child with GA1. In these scenes of interaction between Amish and biomedical cultural worlds, between CSC practitioners and Amish patient families, individuals craft the illness from perspectives of the other as well as the self.

Locating the networks of experiential relationships involved with the body helps us to recognize disease—and genetic disease in particular—in this way. Raspberry and Skinner evoke

this idea in their discussion of the genetic body and the “reverberations of meaning that extend across generations into the past and future” (2007:383). As families engage with genetic medicine, they experience both an anatomical and a molecular body. Constituted at these different levels, genetic bodies and genetic diseases are often seen as knowable objects. But both are also unpredictable; phenotypes are influenced and altered by social dynamics at all turns. They are, if you will, *crafted* by the social aesthetic, despite their attribution to roots in the biological.

In other words, experiencing genetic bodies and genetic disease remains situated in relationships. A GA1 family from 40 years ago experienced the aesthetics of that disease in radically different ways than a family today. The Lancaster Amish variant that causes GA1 has not been altered; the ways GA1 and genetic bodies of the Amish are crafted by the social aesthetic have been radically transformed by the social. As Raspberry and Skinner note, “the genetic body transcends the individual corporeal unit and becomes a generational stream of health information, spanning the past, present, and future” (2007:383). In many instances, relationships are thought of as primarily familial despite including larger social relationships as important factors in these intergenerational reverberations. But for the Lancaster Amish, the genetic body further blurs the social/natural dualism by extending out into the collective. Individuals and families are more biologically/literally related as well as being more socially/figuratively related by virtue of their participation in cultural worlds of the Amish.

On the one hand, Amish decisions around health technology rest in the hands of parents and families. On the other hand, the body politic ultimately makes those decisions in the way it regulates Amish individuals. The *Ordnung* does not spell out exactly which genetic screening is allowed, precisely what pattern for dresses women should utilize, or exactly what symptoms

should receive herbal remedies. Instead, it is the community practice in the everyday—both at its formal twice-yearly ratification and at its daily observance—where that fluid set of principles guides the work of artifacts and use of technology. In this regard, negotiations about when or how to use a particular medical technology become something other than simple choice-making on the part of one party or another. One aim of regulation is to make individual power or decision-making incongruous with the social whole; the strength, sovereignty, and independence of the collective stands in inverse proportions to that of the individual. This description is part of the conceptual basis leading toward a paradox proposed by T.M.S. Evens in his work on the Kibbutz. “Should the individual *choose* to give over autonomy to the collective, granted that this choice remains ever open to the individual, does the individual not deliver the absolute autonomy of the collective and constitute his or her own freedom at the same time?” (1995:93).

This approach establishes the *area in-between* such an individual/society dualism and characterizes that space as a shared “ethical identity” that echoes a Rousseauian general will. As a result, the individual expects to comply with the will of the collective “on both rational and moral grounds . . . a choice for the collective is, by definition, a selfless choice” (Evens 1995:94). Evens encourages the reader to consider that one basis of that general will denotes a preexisting social decision with which the individual can choose to comply; this does not remove the possibility of an individual refusing to comply but supposes like-mindedness from the collective and thereby renders the condition of rational choice unnecessary (Evens 1995:97-98).

The essence of a regulatory body politic and this in-between space of ethical identity are self-replicating, constantly reconstituting spaces that host Amish negotiations around technology. When I approached Amish consultants with the plural medicine decision matrix and asked them to rank where CSC fell on these seven spectra, many of my key consultants would not follow the

exercise through. Despite having pulled the seven categories straight from textual analysis of their interviews and discussions, many came back to summing it up as a “feeling” about why they choose certain modalities and why CSC remains so well integrated into the Plain worlds around Lancaster. The father of one GA1 child put it this way:

“All those things count—the cost, and how long things take, things like that. But I don’t think about or worry on it too much. It’s all these things but when you put them together, it’s something bigger. There’s just *something about* Morton’s clinic. You can’t quite put your finger on it but once you’re in the door—well, our people know we’re in the right place for help.”

It is not tradition that sends an Amish family to the Clinic for Special Children month after month. The individual, rational choice to do so has been made moot by CSC’s ability to access that space in-between the Amish individual and the collective identity.

Baptism as Sacrifice

The third area where Amish cultural worlds bear upon personhood is perhaps the most explicit: baptism. For the Amish, baptism requires sacrifice of western individualism: subsuming the individual in Amish life in a pattern antithetical to western ontologies. And this movement is made possible by the realization/expression of the self via *Rumspringa* and the subsequent sacrifice of self-interest. A young Amish person must excise, cover, and sacrifice the autonomous self in order to be welcomed by the community and thereby receive cultural and spiritual salvation—saving from the world, saving from life into eternal death.

Implicit in the ideas of space, regulation, and negotiation discussed above is the assumption of voluntary inclusion on the part of the individual. In other words, the overlapping areas of Amish individual, social, and bodies politic could not emerge as such if the actors were not present to their own will. Adult confession of belief and subsequent baptism were among the

issues at the heart of the Anabaptist movement in the early 16th century. Nearly a century after these heretic “re-baptizers” emerged from the reformation, Anabaptist leaders generated eighteen articles of faith called the Dordrecht Confession. This confession of faith remains a central set of guidelines for Amish churches across North America. Although the *Ordnung* is maintained orally, the Dordrecht Confession provides foundational guidelines on Anabaptist living and often is used during baptismal candidacy (Kraybill et al. 2013:63). The seventh article addresses baptism:

Concerning baptism we confess that all penitent believers, who, through faith, regeneration, and the renewing of the Holy Ghost, are made one with God, and are written in heaven, must, upon such Scriptural confession of faith, and renewing of life, be baptized with water, in the most worthy name of the Father, and of the Son, and of the Holy Ghost, according to the command of Christ, and the teaching, example, and practice of the apostles, to the burying of their sins, and thus be incorporated into the communion of the saints; henceforth to learn to observe all things which the Son of God has taught, left, and commanded His disciples.¹⁹⁸

The key phrase here—“upon such Scriptural confession of faith, and renewing of life”—calls for a thoughtful decision on the part of a “penitent believer.” In a church set up to be, in part, a dissident voice in Christian opposition to the State, only adults had the capacity to renounce those ties and confess fully to church discipline. As the most prominent Anabaptist theologian of the 20th century, John Howard Yoder, noted, baptism in the Anabaptist faith creates a “status equality” that does not deny social differences but fully relativizes social differences and rejects the discriminatory impact of differences between individuals. In other words, trust is not placed in the individual’s changed insights after baptism or other sacraments. Instead, “the forum for decision is the moral independence of the believing community as social body.” Subsequently, individuals gain dignity through their uniqueness *as* specific members of that body (1991:40-42).

¹⁹⁸ This translation taken from Braght (1938:30).

The confession continues, in the eighth article, by notably defining the subsequent church as formed from baptized members. One of the key phrases in this passage comes at the end: “this church, we say, may be known by ... the fruitful observance, practice, and maintenance of the true ordinances of Christ which He so highly enjoined upon His disciples.”¹⁹⁹ This directs Amish church discipline explicitly to the Gospel and Apostolic teachings, thus creating a religious tradition basing many of its community rules of order on these portions of biblical teaching²⁰⁰.

Adult baptism as a rule leaves children and adolescents outside of membership in the church and creates a liminal ground where they transition into both adulthood and full participation in the church community. For a “penitent believer” to enter the church “upon such Scriptural confession of faith” requires an intense individual decision. Some argue that acculturation via Amish rearing practices help remove the freedom to truly choose but this smacks of universalism. It is uninteresting to point out that Amish children are clearly reared with the intention of shaping faithful and dedicated Amish church members. However, this training coupled with the potential consequences of turning their backs on their families and communities can make for convincing motivators to choose baptism.

¹⁹⁹ Full translation, in Braght (1938: 30-31):

We believe in, and confess a visible church of God, namely, those who, as has been said before, truly repent and believe, and are rightly baptized; who are one with God in heaven, and rightly incorporated into the communion of the saints here on earth. These we confess to be the chosen generation, the royal priesthood, the holy nation, who are declared to be the bride and wife of Christ, yea, children and heirs of everlasting life, a tent, tabernacle, and habitation of God in the Spirit, built upon the foundation of the apostles and prophets, of which Jesus Christ Himself is declared to be the cornerstone (upon which His church is built). This church of the living God, which He has acquired, purchased, and redeemed with His own precious blood; with which, according to His promise, He will be and remain always, even unto the end of the world, for consolation and protection, yea, will dwell and walk among them, and preserve them, so that no floods or tempests, nay, not even the gates of hell, shall move or prevail against them—this church, we say, may be known by their Scriptural faith, doctrine, love, and godly conversation, as, also, by the fruitful observance, practice, and maintenance of the true ordinances of Christ, which He so highly enjoined upon His disciples.

²⁰⁰ Although the Amish still incorporate the Dordrecht Confession into their regular church discipline, many other Anabaptist sects no longer rely on it so heavily. Many Mennonite groups, for example, have created updated and new confessions but still honor and consider the historical iterations. The most recent and widely used in mainline and progressive Mennonite churches is titled *Confession of Faith in a Mennonite Perspective* and was adopted in 1995.

If the mutual separation within Amish communities embeds itself so thoroughly in Amish experience as I suggest above, it is not surprising that the retention rate remains so high. Most sources place attrition around 10%; one or two kids out of every ten is likely to leave the Amish community. Many of these head to less conservative Mennonite or other Christian churches and fewer move into a secular lifestyle. It is a myth that young adults will be shunned or banned if they decide not to join the church. But depending on the character of their particular *Gmay*, they may be convinced that this is a sin leading to eternal punishment or they may simply be in danger of offending their family members in the manner of any adult child's turning away from his parent's teachings. Either way, the risk of shunning is mitigated by choice at baptism, but it is that same risk that makes baptism a weighty gamble for the unconvinced. Once someone does go through with joining the church, subsequent sin or offence against the *Ordnung* is indeed punishable by ban and shunning.

Rumspringa, the period between childhood and marriage, is well known to the English due to its depiction in movies, on "reality" television programs, and in Amish-themed romance novels²⁰¹ or other fiction. This period is frequently misrepresented²⁰² in many of those contexts where Amish youth are depicted as living hard-partying lives with few consequences and having to struggle between joining the church or never seeing their families again. In reality, *Rumspringa* varies quite a bit depending on the settlement, district, and affiliation. Just like relative conservatism among Amish churches, characteristics of *Rumspringa* often reflect locally-produced practices and standards around what this period should include. There are some

²⁰¹ "Bonnet Rippers" are an unfortunate genre, in my opinion, but an eloquent and thorough treatment of these phenomena was published recently with the clever title *Thrill of the Chaste* (Weaver-Zercher 2013).

²⁰² Kraybill et al. (2013:213-216) outline seven myths of *Rumspringa* that have been created and perpetuated by outside stereotypes and media portrayal of the Amish.

kids, indeed, who experiment with drugs, alcohol, and sex. There are many who experiment with things like owning a car, buying trendy clothing, living on their own, having a facebook page, texting with their friends, or cutting their hair. Still others spend the time attending more youth events and hang out with their friends frequently. The spectrum is very wide.

An Amish friend arranged for me to drive a group of seventeen year old girls to a Sunday evening singing one week. Pulling up to the farm house, they came streaming out in various states of jumbled cultural materials. One girl had belted her plain dress with a wide leather belt with a silver buckle. Another wore a loudly-patterned Tommy Hilfiger coat while a third had shimmery little gold balls in her newly pierced ears. All three of them were attached to their cellphones the entire ride with thumbs flying through long strings of texts and their conversation weaving in and out of Pennsylvania Dutch. They were alternately quiet, awkward, brassy, and animated. Save for the delicate organdy *kapp* fixed atop each of their heads, they might be mistaken for English teenagers.

Rumspringa, or “running around,” begins around age sixteen or seventeen. This is a true liminal period. These adolescents enter into a world where they are “neither Amish nor English, neither children nor adults” (Kraybill et al. 2013:223). They are generally not held accountable for their actions in any formal way from within their families or communities, although most will respect their parents’ rules, homes, and property. But, for example, a teenager can show up to a mud sale in English-style clothing she bought at the local mall, spend the entire time texting on her phone with her friends, post some selfies to Facebook, and sit around her parents’ living room later planning a beach trip with her girlfriends. None of this would receive comment from her elders. Even infractions of the law are not typically dealt with by parents or church members; underage drinking or destruction of property may go on freely as long as the kids don’t get

caught directly by municipal authorities. These young adults have the opportunity to exercise English sensibilities and experiment with western individuality in ways they could not have previously fathomed. *Rumspringa* ends at marriage, not baptism, although the two frequently happen in conjunction with one another. The rite of marriage transforms a child into an adult; the rite of baptism transforms the child into an Amish church member.

At baptism, the Amish commit themselves to the *Ordnung*, the order of rules for community life, and simultaneously undertake redirection of individual identities into the group. This commitment requires them to leaving behind any practices, interests, and behaviors they may have developed or expressed during the period of *Rumspringa* (Beiler 1982). The rite itself happens during a regular church service. Not unlike the earlier description of the penitent sinner sitting physically supplicated during church, those wanting to get baptized also sit hunched over during this service as a physical sign of yielding to the church (Kraybill et al. 227). The candidates are asked a series of questions, the last of which looks like this:

Do you promise before God and His church that you will support these teaching and regulations [*Ordnung*] with the Lord's help, faithfully attend the services of the church, help to counsel and work in it, and not to forsake it, whether it leads you to a life or to death? (Kraybill et al. 227)

After agreeing to this dedication to upholding the collective identity of the group, the Bishop recites the prayer used for this rite, summarizing the supplicants' move to "renounce the devil, the world, and their own flesh and blood." With that and an anointing by water, the possibility of maintaining an autonomous or unconstrained selfhood is sacrificed and rejected. This is a powerful practice that shapes the social order as Amish communities negotiate the non-Amish world around them.

Just as Latour might tell us that the modernity we believe to be a consequence of conquering science is actually a question of faith, the Amish constant negotiation with science

and technology is overtly recognized as faith-based. But not only faith-based in a theological sense where many decisions are made in light of religious doctrine, but simultaneously faith-based in the sense of a body politic that maintains the ability to negotiate science on behalf of the group. At the point of baptism, the combined forces of the habitus, community discourse, and strictures of the *Ordnung* become the most powerful source of cultural guidance about selfhood and the body. In light of this brand of modernity, the Amish incorporate the present in a way as not to destroy the past or alienate the future.

Conclusion

I started this chapter by asking how the bounds and influence of Amish cultural worlds would bear upon personhood. Amish embodiment, the use of a local body politic to regulate the cultural world, and the self-sacrifice required in Amish baptism are all ways in which the potential for Amish personhood is formed in practice. Looking for a negative case remains key to rounding out this whole picture. To start with the individual body, nowhere is this more impacted than in the adults with GA1 injuries. They live with high dependence on caretakers, are reliant on wheelchairs, and are often unable to communicate effectively. The presence of these individuals presents a certain incongruity with the Amish model for laminated group identity across the *Gmay* that is demarcated by cultural artifacts, ability to labor, participation in worlds of craft, and embodiment of Amish time through space.

Don't mistake—disabled adults are generally well cared for in the community but they are incompatible with the way Amish bodies are typically reflected in the social. They are often laden with cultural artifacts that are unique—motorized wheelchairs, hearing aids, and other assistance—arresting some of the possibility to serve the community as a part of the whole. They

possess no ability to labor or participate in a craft economy in any way, thus rendering them unsuitable for enacting the roles of a participatory community member. This may leave them in a perpetual state of being *Special Children*. For some, this is both necessary and appropriate. But others are relegated to a life of where physical disability results in full social disability—most are given few or no opportunities for occupational therapy, for computerized voice translators, or for any other measures that might assist them as *able*.

Keeping these individuals as children allows the body politic to maintain regulation of Amish bodies in familiar ways. Among the people that I spoke with who left the Amish community (either by excommunication or by choosing not to get baptized), a surprising number of those had some sort of disability that radically altered their ability to operate in an Amish community as a fully-recognized adult. They were unable to sink into the laminated whole because of their marked difference and inability to execute the proper roles of a baptized Amish church member.

The dedication to *Gelassenheit* works to join Lancaster Amish communities together as their boundaries of autonomy are attenuated through sacrificial baptism. The collective identity eschews individualism, strengthening the social body by stringently enforcing *Gelassenheit* as a yieldedness of self-will for the benefit of the *Gmay*. Subsequently, Amish collective identity can be understood then as constituted by an assemblage of yielded “selves”—the individual bodies regulated by the body politic. In other words, as a singular Amish person dedicates him or herself more stalwartly to the concept, the greater that individual may meld into a collective Amish, and the more deeply laminated that community becomes.

When an Amish consultant talks about how they like to “do it our way” and how it is “ingrained in us to be self-sufficient,” this “self” becomes less and less the individual person.

Amish group identity, understanding of the body, and bodily practice reflect epistemological paradigms that contrast in important ways from those presumed by Cartesian assumptions about embodiment. These culturally-defined bodies become sites where the areas between nature/culture or subject/object emerge. This involves struggling against continued separation of mental, subjective experience and bodily, objective experience in order to deemphasize the cultural-biological divide (Latour 1999). This struggle aims to advance understanding on forms of “lived embodiment in the fields of practice in which they take form,” (Farquar and Lock 2007) and presents the opportunity to begin reading the implications of actants on bodily practice and group identity.

Last Thoughts

By now it has been well-established here that the Lancaster Amish exist in a dialogic relationship with forms of technology—one where they incorporate tenets of patience, careful consideration, and calling to God’s will when deciding what forms of technology may be appropriate for use in the community. This acceptance or refusal of any particular technological change helps shield communities from a kind of modernity they perceive as threatening to their corporate life (Kraybill 1994b:33). This kind of choice-making at the group level is described here as a chief characteristic of their own alternate modernity²⁰³.

The *Gmay* remains sensitive to potential consequences associated with various innovations and thereby attach extensive logics to their decisions about technological incorporations. The factors at play in these decisions sets the stage for understanding Amish

²⁰³ See (Escobar 2008) for theories of modernity—particularly his second path to modernity: the alternate modernities where people at local levels engineer their own path into and through “the modern” using the group’s knowledge, resources, and experience.

negotiations of medical technologies. The model at CSC, for example, gives us a stark illustration of a space where genetic medicine has been scaled down and adjusted to culturally appropriate standards for a community that grapples with utilization of current technology; but also a stark example of currently functioning integration of genomic knowledge and clinical application. When mapping areas of confluence on the decision making matrix (see appendix 2), to reflect practice at CSC, the spots move over in almost every category—away from the biomedical standard toward fundamentals considered more favorable among Lancaster Amish.

This dissertation has discussed concepts of an Amish collective identity made manifest by the concept of mutual separation and the *Gmay* as the social body where primary identity gets constantly formed, fortified, and enforced as it serves to minimize the autonomy of individuals in favor of group practice. This emergent strength of the district stitches together the patchwork of Amish cultural worlds across the Lancaster area. The mutual separation found within this kind of group reflects a stringent giving up of self-will for the benefit of community as the *Gmay* actively abjures individualism and views the body as a spiritual home suited to experience within group-dictated boundaries. Therefore, a collective sense of what it means to exist as an Amish person is not a product of isolated, deliberate processes of cultural production but dialogically shaped within communities of practice and constitutive of this cultural world (Holland et al. 1998; Holland and Lave 2001). As collections of Amish individuals participate in these religious, familial, and community-based groups, they form senses of self in these realms relative to the participation in that community of practice.

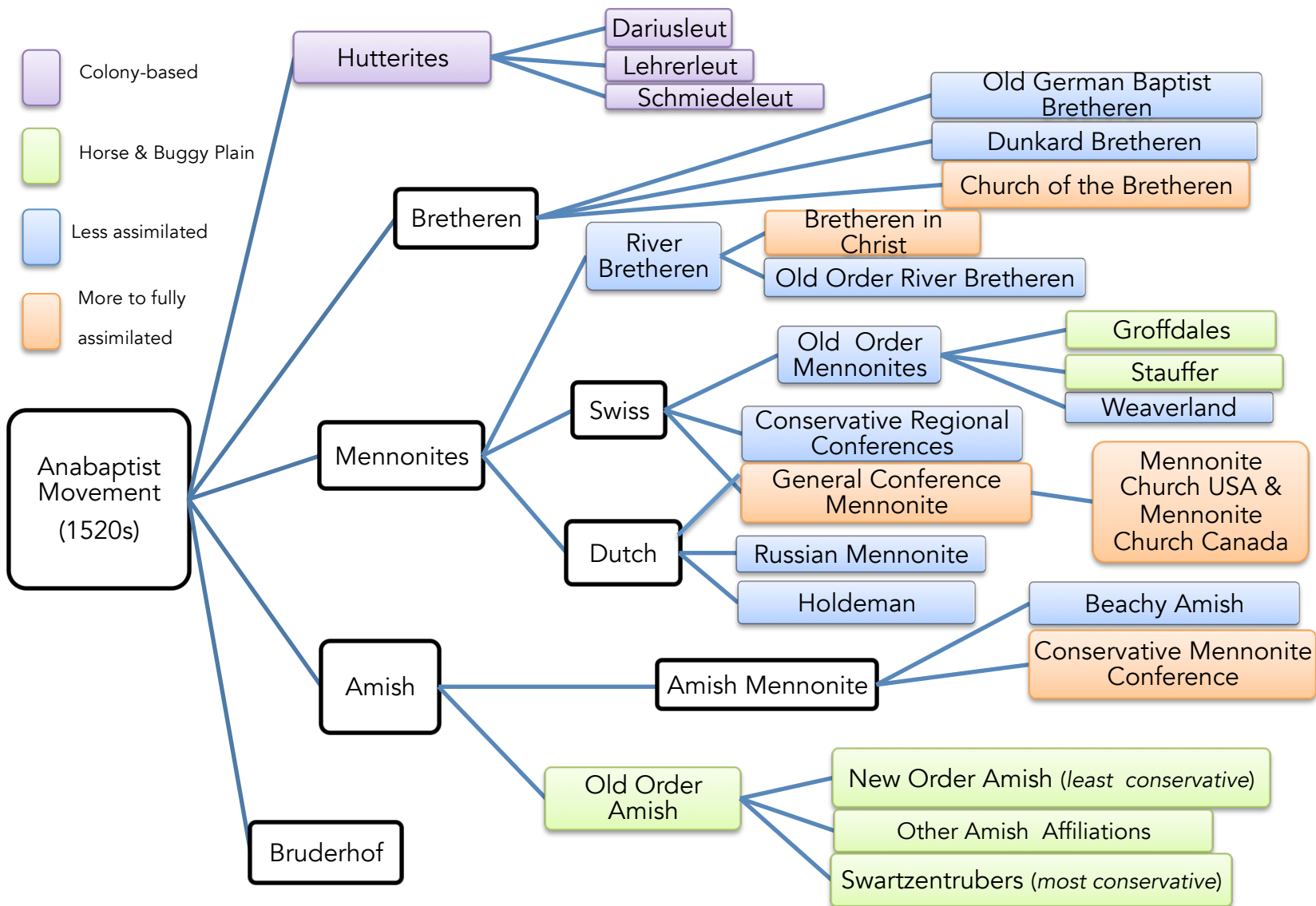
The collective sense that is produced and internalized by the Amish through their actions and obligations in the *Gmay* renders them a laminated cultural whole that irreparably binds its members to the identity of the group. Elements of this lamination have been depicted here as

rendering the Amish fundamentally different from the English. In some regards, this is a true consideration, but it should be noted that the Amish themselves (despite their unique forms of alternate modernity) are still a product of Western European history and social change. The Amish church and other Anabaptist groups still exist as forms of Christianity, even if they exist in the minority and with relative distinction. As a result, Amish self-definition certainly depends on their rejection of the English community, thus making the latter a negative component of being Amish. But negating the English remains an indispensable component nonetheless. Even though the individual self is profoundly constrained, it remains always present by virtue of that constraint and as a function of (re)baptism. It is worth remembering that the modern Western individual is also a social phenomenon—each person is always already a self-other relationship. Different from the Cartesian case where the self is primarily autonomous, the Amish offer us a window into Western communities where identity may be constructed foremost as a part of the laminated group.

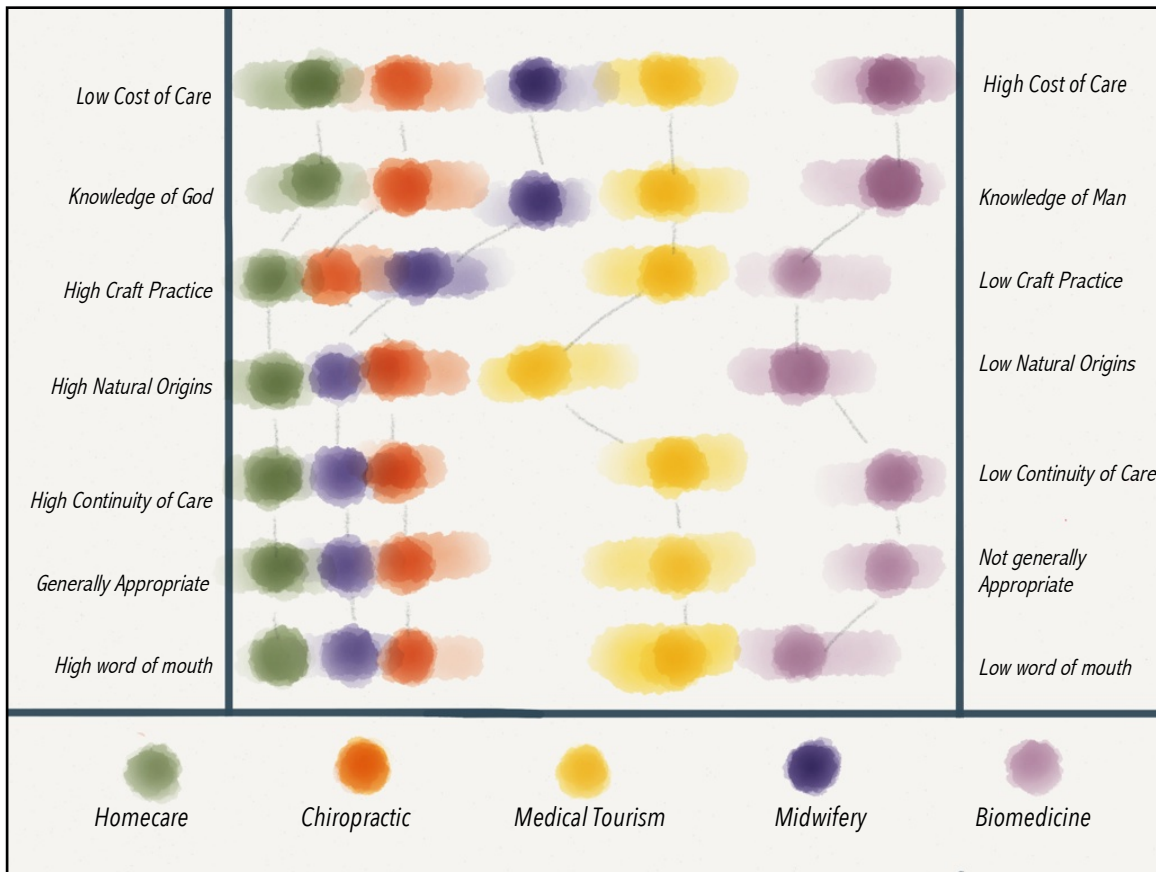
The pluralistic model of health built and practiced by Amish communities and their relationship with the Clinic for Special Children provide nested case studies investigating ways that these tenets of Amish life create both physical and conceptual spaces of practice. Within these spaces, the Amish experience tensions that arise between the self and the community, among the community and the outside, and around the artifacts that populate their cultural world. Indeed, normative health practices and the suitability of health technologies are intensely impacted by the space of practice where Amish collective identities emerge.

Du brauchsch des Blatt nimmi drehe—fer des iss es End

Appendix 1: Spectrum of North American Anabaptist Groups



Appendix 2: Decision Matrix Drawing



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