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Thick Sociality: Community, Disability, and Language in Spinal Cord Injury Rehabilitation

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Thick Sociality: Community, Disability, and Language in Spinal Cord Injury Rehabilitation

A dissertation submitted in partial satisfaction of the
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in Anthropology

by

Molly Josette Bloom

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ABSTRACT OF THE DISSERTATION

Thick Sociality: Community, Disability, and Language in Spinal Cord Injury Rehabilitation

by

Molly Josette Bloom
Doctor of Philosophy in Anthropology
University of California, Los Angeles, 2020
Professor Norma Mendoza-Denton, Chair

While anthropologists have long theorized disability, few studies have outlined the dynamics of communities centered around disability. This dissertation addresses this gap by providing an anthropological analysis of a disability community, attending to the daily, often creative, linguistic practices within these spaces. By examining the disability community at a public rehabilitation hospital in Southern California, this research explores disability as a *process*. Rather than approaching impairment as a classification of biological lack, this dissertation locates disability in everyday conversations and the interplay of historical, sociopolitical, institutional, economic, ethnic, and ability ideologies. It draws on and contributes to the fields of linguistic anthropology, disability studies, and the growing cannon of disability anthropology.

Through an analysis of the linguistic dimensions of stance and participant framework in the everyday language, I demonstrate that disabled people socialize each other into unconventional, sometimes subversive, orientations to each other and to impairment. I propose the theoretical concepts of “disability habitus” and “thick sociality” to describe the dynamics of the rich, historically grounded community at the hospital, where people come not just for medical care, but to participate. I argue that disability is an interactional process. I further argue that a history of disenfranchisement and biopower paved the way for the present neoliberal social context.

Analysis in this dissertation reveals that disability is generative; it opens new possibilities for interaction and subjectivity. This is the first study that endeavors to shed light on disability community in the context of rehabilitation. Rather than examining rehabilitation as practice of only trained (often able-bodied) medical professionals, this study takes an ethnographic approach to examine the sense of community among disabled people. This is important because research in the field of rehabilitation has not attended to the potentially transformative impact of disability community on people coping with injury.

The dissertation of Molly Josette Bloom is approved.

Salih Can Açıksöz

Marjorie Harness Goodwin

Cheryl F. Mattingly

Elinor Ochs

Norma Mendoza-Denton, Committee Chair

University of California, Los Angeles

2020

TABLE OF CONTENTS

LIST OF FIGURES AND TABLES

TRANSCRIPTION SYMBOLS

< >	Transcriber comment; nonvocal noise; physical action
…	Part of dialogue excluded from transcript
.	End of intonation unit; falling intonation
,	End of intonation unit; fall-rise intonation
?	End of intonation unit; rising intonation
!	Raised pitch and volume throughout the intonation unit
↑	Pitch accent
CAPS	Emphatic stress; increased amplitude
:	Vowel/ consonant lengthening
=	Latching; no pause between intonation units
-	Self-interruption; break in the word, sound abruptly cut off
(.)	Pause of .5 seconds or less
(n.n)	Measured pause of greater than .5 seconds
@	Laughter; each token marks on pulse
n@	Nasal laughter
h	Outbreath (e.g., sigh); each token marks one pulse
.h	Inbreath
[ ]	Overlapping speech
( )	Uncertain transcription
° °	Quiet speech
“ ”	Reported speech or thought
XX	Indecipherable speech

COMMON ABREVATIONS

ADA	Americans with Disabilities Act
Cath	Catheterize
IRB	Institutional Review Board
L.A.	Los Angeles
OT	Occupational therapy
Para	Paraplegic
PT	Physical therapy
Quad	Quadriplegic (see also tetra)
Rancho	Rancho Los Amigos Rehabilitation Institution
Rehab	Rehabilitation
RT	Recreational therapy
SCI	Spinal cord injury
SSA	Social Security Administration
SSDI	Social Security Disability Insurance
SSI	Social Security Income
TBI	Traumatic brain injury
Tetra	Tetraplegic (see also quad)
UTI	Urinary tract infection

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This project was only possible with an unending network of kindness that has helped me along the path in preparing for, conducting research, and writing this dissertation.

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My disability communities have inspired this project and made the dissertation possible. The thoughts presented are in dialogue with the rich and energetic collection of minds that I have encountered in the many different spaces that disability communities inhabit, such as rehabilitation hospitals, adaptive athletics, disability studies conferences, and even those backstage places in which we encounter each other (waiting for the accessible shuttles, in line for the elevators). Thank you, especially to the folks at Rancho who paved the way for this dissertation, including Dr. Philip Requejo, Dr. Yaga Szlachcic, Linda Sutherland, Bobbi-Jean Tanberg, David, Elizabeth (who fueled my brain with the best homemade Mexican wedding cookies) and Ed. Your words, thoughts and ideas have shaped this project.

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PREFACE

“When normals and stigmatized… enter one another's immediate presence, especially when they there attempt to sustain a joint conversational encounter, there occurs one of the primal scenes of sociology; for, in many cases, these moments will be the ones when the causes and effects of stigma must be directly confronted by both sides.”

-Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity* (1963, 13)

What is stigma? How does one deal with stigma - emotionally, psychically, physically and interactionally? What happens to a sense of identity and self when a taken for granted embodiment is shattered and one must rehabituate (Manderson 2011) to new circumstances (for instance, when someone sustains a spinal cord injury and finds themselves dependent on a wheelchair for mobility, on catheters for urinating, on enemas for defecating, on sexual aids for sexuality, on others to help move in and out of the wheelchair)? This dissertation is an exploration of rehabilitation from injury, particularly spinal cord injury (SCI), in a setting in which impairment is generally socially celebrated, and disability marks one as an insider, not stigmatized. This dissertation examines the interactions that structure that sense of social acceptance and *community*.

One groundbreaking sociologist with wide influence in anthropology on the topic of stigma and disability has been Erving Goffman. In *Stigma: Notes on the Management of Spoiled Identity* (1963), Stigma is an undesired difference, a blight of character or body that breaks the course of polite interaction through which individuals routinely come into contact. People manage this stigma in social interaction. Countless ethnographic examples depict stigma as percolating to the consciousness of each interlocutor and deeply influencing the course of an interaction. It forces parties to hide their awareness, yet stigma is at the forefront of each interlocutor’s minds, thereby, existing in the consciousness of self and other. Stigmatized persons are always faced with managing feelings of being exposed and continually engaged in attempts to minimize their blight in the eyes of others.

Goffman’s writing has spoken to me in many ways. At times, when I was making my way through *Stigma*, it felt like I was reading my own inner dialogue. For instance, he tells a narrative of a girl with one leg who is aware of her obvious stigma in social interactions, though she can make efforts to ignore it, and can encourage her interlocutors to ignore it as well, in conversation. When she knows that someone recognizes her disability and the stigma it entails, she feels vulnerable. She becomes acutely aware of vulnerability when her stigma is somehow highlighted to outsiders. When she falls in a public place, she is aware that she is perceived as especially helpless and begrudges the swarm of people coming to her aid (Goffman 1963: 16-17). As a person with a visible disability, in particular, living as a woman with one leg and a wheelchair user, Goffman’s explanation resonates deeply.

Yet, at other times, Goffman’s work seems removed from my own experiences and those which I have observed among my disabled friends, peers and interlocutors. Despite his thought-provoking work, the interactions upon which he focuses seem to center around white, middle class norms. Furthermore, he is flippant and dismissive about the identity work which happens when disabled persons interact with each other, noting that interactions can help stigmatized people feel ‘normal:’:

> Among his own, the stigmatized individual can use his disadvantage as a basis for organizing life, but he must resign himself to it to do so. Here he may develop to its fullest his sad tale accounting for his possession of the stigma… On the other hand, he may find that the tales of his fellow sufferers bore him, and that the

> whole matter of focusing… in short, on the "problem," is one of the large penalties for having one (Goffman 1963, 21).

In Goffman’s near stream-of-consciousness, meandering prose I find myself both understood and viscerally enraged. On the basis of my own experience and ethnographic field observations for this dissertation**,** I affirm Goffman’s claim that, in a group of ‘fellow sufferers,’ a stigmatized person can learn the group narrative through which stigma is minimized, but wholly rejects his claim that such interactions are examples of people ‘resigning’ themselves to ‘half-worlds.’ This dissertation is a response to Goffman’s claim that a group of ‘undesirables’ is a less full social world. Surely, stigma may drive people together. But that space in which those people come together can be rich, full of social dramas that thicken life plots; it mirrors the social world of desirables, but, most excitingly, it can be subversive.

VITA

Education

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2019	Bloom, Molly. “Creating Disability, Creating Community: Disability in Medical Anthropology.” *Medical Anthropology Quarterly Online*.
In press	Gediel, Ana Luisa & Molly Bloom. In Press. “The Legitimation of Brazilian Sign Language in Internet Videos.” In *Deaf Empowerment: Toward Decolonization of Sign Language Peoples*, edited by Leila Monaghan and Donald Grushkin.
Forthcoming	Bloom, Molly. “Toward a Disability Anthropology of the Middle East and North Africa.” *Hespéris-Tamuda*.

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2018	“Talking about disability and chronic illness: Disability accommodation interactions” (with Kerby Bennett). James C. Young Colloquium.
2019	““I’m an open book”: Disabled Peer mentors talk intimacy, taboos and transgression”. Society for Disability Studies Annual Conference.
2019	“Disability Sociality: When is Doing Something Doing”. American Anthropological Association Annual Meeting.

CHAPTER ONE – Introduction

Volunteer orientation

On a warm Wednesday in October 2016, I parked my car in one of the many disabled spots at Rancho Los Amigos, referred to affectionately by its many familiars as “Rancho.” Rancho is a rehabilitation hospital in Downey, a suburban municipality in Southeast Los Angeles (L.A.) County. At the time, the institution was a mixture of architectural styles, including Utilitarian and Spanish Colonial Revival buildings (HABS CA-2800), construction as new outpatient buildings were built and decaying buildings razed, and trailers where departments were temporarily relocated. I made my way into the maze of buildings and fencing, meant to keep passersby out of construction zones, into the 800 Building, a gray concrete structure where I would complete volunteer orientation. I pushed into the meeting room and pulled my wheelchair up to a table towards the back. I was eventually joined by four other future volunteers, each with an apparent physical disability.

The orientation was initiated by Sally, the director of Rancho’s Volunteer Services. She expressed her gratitude at having volunteers to keep the hospital running and provide the warmth that made it such a “special place.” The next person to speak was another Sally, but she referred to herself as Little Sally, and told us, “that’s Big Sally.” I assumed Little Sally got her nickname because she was considerably shorter than Big Sally, whose name referred not just to her height, but to her status as “The Boss.” As Little Sally took over and proceeded to lead the orientation, it became apparent that her “Little” name contrasted ironically with her expansive personality and her energetic, mothering demeanor. I was impressed by the knowledge that she demonstrated of the hospital, including the hierarchy, the administrative processes, and the many characters that peppered the institution. As the orientation wound down, she explained the institutional rules that we should follow as volunteers. Some of these included washing our hands frequently for fifteen seconds (which, Little Sally explained, is as long as the Happy Birthday song that she recited for us), getting our tuberculosis test completed every year, our background check every three years, and a flu shot every winter. We also always had to signify our position in the hospital by dressing “appropriately” (which meant not wearing blue jeans), wearing our identification badges, and coming to the hospital clad in our blue volunteer aprons. When our orientation was finished, Little Sally lovingly handed out our aprons, exclaiming, “Don’t those just look so nice and purty!” As I donned my apron for the first time, I signified my position within Rancho’s social fabric: a network of institutional roles, identities and relationships, “semiotic elements of speech, bodily practices, and symbolic exchanges” (Mendoza-Denton 2008, 294), centering around disability that would come to fascinate me for the next several years.

To embed myself in the hospital, I began my volunteering with the KnowBarriers program, which provided free resources and disabled peer mentors to Rancho patients to “empower people with disabilities to create a vision of personal success, build confidence, and achieve life goals” (KnowBarriers, n.d.). The mission of this program echoes the “empowering lexicon” among rehabilitation in Carr’s work (Carr 2009). It is a neoliberal vision of freedom through self-determination that I learned contrasted with the structures of disability, economic and racial disenfranchisement which my interlocutors navigated. For a year, I spent every Friday scanning and compiling “Stroke Survival Guide” to be disseminated to patients. Through this participant-observation as a volunteer, I developed an understanding of some of the intricacies of the hospital at which I would conduct twenty months of ethnographic fieldwork. As I pushed around the hospital in my blue apron, I was attuned to the harmonious, bustling structure of a rich disabled community. Disabled folks came to the hospital for appointments and would spend their entire days there to catch up with friends, get a workout at the gym, catch a class, and meander in the warm Southern California sun while they waited for their “Access rides,” affordable wheelchair accessible shuttling for disabled people.

My place within the community was easy to establish due, especially, to my visible disability. Even before people began to recognize me, other wheelchair users would greet me as though they were greeting an old friend. Clinicians never questioned my presence in the hospital. When I decided I needed to understand more about the structure of Rancho’s disability community, I met with the doctors who oversaw Rancho’s Research Department. They nearly bent over backward to accommodate my project, offering to aid me with their internal institutional review board (IRB) and even help me locate funding, though anthropologists tend to have an ambivalent, if not outwardly critical, relationship with the institutions about which they write. Instead of suspicion when I pitched my project, I was met with warmth. It almost felt as though aiding my project was an act of philanthropy - a gift they could give to me, a disabled person embedded within the fabric of Rancho, wearing a blue apron proudly across my chest. I had been interpellated (Althusser 1971; Butler 1993; 2011) - recognized and “hailed as a particular kind of institutional subject” (Carr 2009, 318). I had the sense that my whiteness and education level positioned me in an institutional hierarchy in which I wielded more power than the peer mentors, most of whom were people of color without access to higher education. Yet my visible disability also made me the recipient of administrative good will and, thus, placed me in an inferior position to the typically white, non-disabled administrators and clinicians. Through interactions with the staff at Rancho, I not simply observed, but re-inscribed institutional power (see Carr 2009). However, as a disabled insider, I also participated in a rich social, sometimes subversive, world that centered around disability. The result is this dissertation, an exposition of my entrance into the disability world (Ginsburg and Rapp 2013), structured by institutional and communal forces, as well as individual and collective linguistic and bodily practices.

While some scholars argue that the anthropological study of disability needs to move away from the clinic and into the community (e.g. Berghs 2012), I felt the need to move into the clinic to understand the disability community.[1] On Rancho's campus, I found a historically grounded disability community. It was a microcosm in which larger social forces were played out in everyday interactions. This dissertation explores disability as a *process* - as an entity that materializes, not because of biological pathology, but through the interplay of sociopolitical, institutional, economic, racial, gender and ability ideologies. It draws from linguistic anthropology, a field based upon the idea that language as symbol and communication as process structure, reify and shift social worlds. It builds on the growing cannon of disability anthropology (e.g. Ablon 1981; Açıksöz2012; 2020a; 2020b; Bloom 2019a; 2019b; Erevelles 2011; Friedner 2015; Ginsburg and Rapp 2013; Hartblay 2017; 2019; Kasnitz and Shuttleworth 2001; Kohrman 1999; 2003; 2005; Murphy 2001; Shuttleworth and Kasnitz 2004), dedicated to the study of disability as "a relational category" (Hartblay 2019), situated within social and historical contexts (Bloom 2019b). It is in dialogue with disability studies, which push against the notion of disability as lack (e.g. Baynton 2013; Davis 2013; Garland-Thomson 2009; Kafer 2013; Linton 2006a; Mitchell and Snyder 2015). Ironically, within Rancho, an institution that

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[1] Aside from the fascinating social configurations of disability at Rancho, I found the need to move into the clinic because I was, in a sense, constrained to conduct fieldwork in a medical environment within the continental United States. I had tried to conduct dissertation fieldwork on disability in Morocco, but found the conditions of the field were too inaccessible as a disabled anthropologist. In order to exit the field with any semblance of mental health, I knew I needed to find a wheelchair-accessible environment with a strong sense of disability community.

approaches impairment as a biological function of lack, I found a community that demonstrated disability as *generative*.

A note about language

While there are many ways to refer to disability and preferences for referential terms differ among disabled people, I have opted for identity-first language (a *disabled person*, rather than a *person with a disability*). This choice reflects my alignment with disability studies scholarship arguing that referring to disability as an integral aspect of identity is an essential step in 'naming oppression' (Linton 2006b). Lawrence Carter-Long, who launched the #saytheword campaign, explains in a *National Public Radio* article (King 2016): "to suggest disability is simply a 'difference' and has no impact on a person's life is a very privileged position to take. Most disabled people don't have that luxury. The assertion flies in the face of reality and minimizes the very real discrimination disabled people face.".

Additionally, I follow Schalk (2018) and Price (2015) in referring to the 'bodymind,' rather than simply the 'body' or 'mind.' I take inspiration from Schalk's insistence "on the inextricability of mind and body and highlight[s]… how processes within our being impact one another in such a way that the notion of a physical versus mental process is difficult" (Schalk 2018: 5).

Field site: Rancho Los Amigos

Fieldwork for this dissertation was carried out at Rancho Los Amigos Rehabilitation Hospital, a publicly funded hospital where people undergo rehabilitation following acute care for disabling injuries. Rehabilitation is described by the World Health Organization (2018, 1) as "a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment.". As a rehabilitation institution, the hospital is exceptional. It is nationally renowned for its treatment of Spinal Cord Injury (SCI), though it also specializes in traumatic brain injury (TBI), stroke rehabilitation, and post-polio care. Patients with other conditions in need of rehabilitation may be admitted, depending on the demand in L.A. County. The focus of this research, the SCI community, emerged because of the prevalence of SCI patients at the institution. Rancho is one of fourteen Spinal Cord Injury Model Systems[2] and ranked as one of top ten institutions for SCI rehabilitation and research in the country. This nationally recognized status is a form of symbolic capital (Bourdieu 1984; 1998), a marker of prestige that makes it a premiere choice for people who have sustained SCI in Southern California, drawing approximately 350 SCI inpatients per year.

Rancho is in the municipality of Downey, a majority Latinx, middle-class city in southeast Los Angeles County. The institution describes itself as treating an "under-served population" (Rancho Los Amigos Rehabilitation Center, n.d.). A majority of the hospital's SCI patients are "economically disadvantaged" (Rancho Los Amigos Rehabilitation Center, n.d.). In 2015 and 2016 (the most recent statistics to which I had access), 61% of patients had Medi-Cal insurance (Lewthwaite 2017), public health coverage available to American citizens with demonstrated financial need. In addition to serving a population with limited economic resources, the hospital also serves a large group of ethnic minorities. Of the traumatic SCI inpatients in 2015 and 2016, 42% were Hispanic (compare to the national average of 13.2%); 30.8% were white (national average - 59.5%); 19.6% were black (national average - 22.6%); and 7.5% were Asian (national average - 2.8%) (Lewthwaite 2017; National Spinal Cord Injury Statistical Center 2019) (see Figure 1.1). Most SCI patients at Rancho are male (87.3% men with

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[2] SCI Model Systems hospitals are funded for research and treatment by the National Institute on Disability, Independent Living, and Rehabilitation Research. As a Model System hospital, Rancho contributes to a national database of research on SCI.

traumatic SCIs in 2015 and 2016, compared to 12.7% female), a pattern that is common nationally (78% of new SCI cases since 2015 are male; 22% are female) (Lewthwaite 2017; NSCISC 2019).

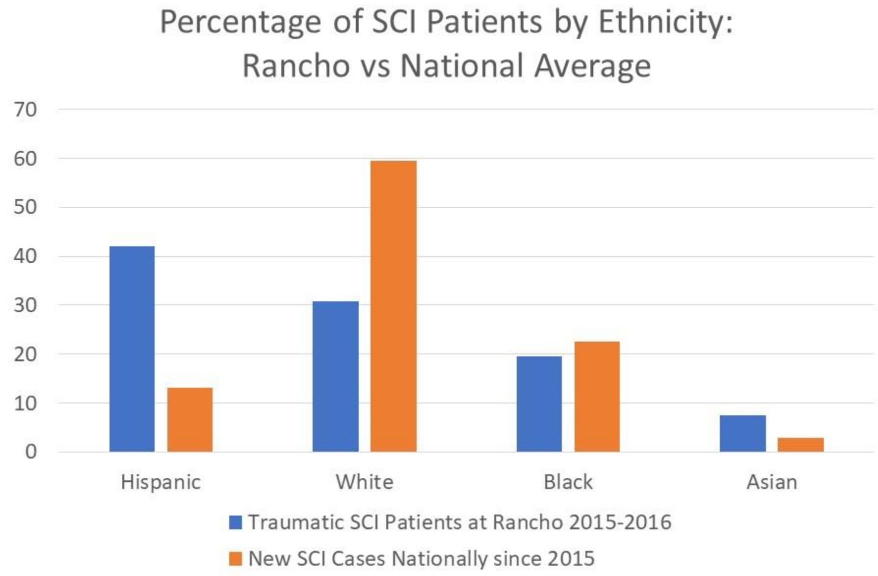

Figure 1.1: Comparative bar graph of Rancho SCI patients and national average. The graph depicts percentages of traumatic SCI patients at Rancho between 2015 and 2016 (blue) and new SCI cases nationally since 2015 (orange) broken down by the ethnic groups reported by Rancho (statistics from Lewthwaite 2017; NSCISC 2019).

This dissertation focuses on the rich disability community at the hospital, which dates back to the opening of the institution in 1888 as the L.A. County Poor Farm. This historically grounded community comes through in Gelya Frank's (2000) life-history of Diane, a congenital quadruple amputee who lived at the hospital from 1964-1968. Here is a recollection from Diane about Rancho that demonstrates her immersion into the underground 'crip' culture:

> After the dinner trays were picked up, I took off with Christie and others as far away from the 500 area as possible. We usually ended up at the 'fish pond' or the

> 700 area where all the good-looking spinal cord injured men were. The equivalent of our parents stepping out onto the porch and yelling their child's name in order to bring them inside was hearing our names being blasted over the paging system: 'Diane Fields, return to your ward. You have visitors.' After they finally realized the purpose for my timely escapes, and found themselves making this announcement too frequently, the pages went something like this: 'Diane, return to your ward… now.'… A few times I failed to send out a 'scout' and almost missed a visit with my father. However, unlike Irene, he would go looking for me. Fortunately, he never found me in any compromising situations" (Diane DeVries via Frank 2000, 33).

The rich social relationships, entanglements and attachments among disabled people to which DeVries alludes are woven into Rancho's social fabric. I followed the threads of this community during dissertation fieldwork by spending time with interlocutors who appeared to have an emotional attachment to the hospital. Nearly all the participants enrolled in the study were disabled folks who spent at least five hours at Rancho per week. Some scholars have remarked on affect associated with rehabilitation. For instance, Açıksöz (2012, 10) notes that, among disabled war veterans in Turkey, the rehabilitation clinic "was nostalgically recalled as a space of camaraderie, shared suffering, and even mischievous leisure." The present study is the first to explore a rehabilitation institution solely from the perspective of the disabled folks who inhabit it. My time was split between two populations: a group that I call "community members" (disabled people who contributed actively at the hospital but did not have formal employee positions); and peer mentors.

Another reason that the hospital is exceptional is that it funds a peer mentor program. The program, KnowBarriers, has a workforce of employed and volunteer mentors, people with disabilities, such as SCI, who provide support, resources and solidarity to newly injured patients. Peer mentors are valued for their expertise of life with a disability (Standal and Ejgil 2008). The peer mentor model is a growing phenomenon in rehabilitation settings (World Health Organization 2013). Though research is limited, this mode l is appealing to the field of rehabilitation, as there is growing recognition that disabled folks possess a wealth of knowledge. One of two founders of KnowBarriers and the present Executive Director, BJ, a woman with a SCI and former wheelchair basketball player, recounted that she learned how to live and function with her disability from the disabled peers whom she met through sports. As a recreational therapist at Rancho in the early 2000's, she had realized that inpatients were unlikely to be integrated into a network of disabled peers, as she was through sports. She helped to create a program of peer mentors, formally initiated in 2009 on a volunteer basis and funded in 2011 (making it one of the only peer mentoring programs in the world to provide wages). Currently, Rancho maintains a crew of peer mentors (both paid and volunteer), who are people with disabilities using their lived experience to provide what they describe as "hope" and "guidance" to inpatients and outpatients in various phases of post-injury adjustment. As one mentor explained, the main duty is to "show the patients, look, there is life after something like this… And… showing the patients by example, that you can drive again, you can go back to work, you can go back to school, you can put yourself out there. It's not going to be that bad. Setting them up with little tricks."

Problem statement

Though spinal cord injury affects a small number of people relative to other physical disabilities (about 11,000 people annually), it is a heavily studied phenomenon in medical and rehabilitative research “because within a moment in time, SCI causes profound changes in virtually all physical systems and functional abilities. Further, the majority of people who sustain new injuries are young adults with a lifetime of experience ahead of them” (Crewe and Krause 2009, 289). It is precisely because these changes in bodily functions associated with SCI, which include possible changes to mobility, independence, bowel, bladder and sexual functioning, as well as increased risk of ulcers and conditions like autonomic dysreflexia, are often difficult to cope with that a disability community is potentially powerful in a rehabilitation setting. This condition has been tangentially addressed in literature on peer mentoring. Preliminary studies, though limited by non-robust, small-scale methodology (Divanoglou and Georgiou 2016), suggest the following impacts: enhanced quality of life (Beauchamp et al. 2016; Sherman et al. 2004); increased probability of obtaining employment (Shem et al. 2011); enhanced self-efficacy (Ljungberg et al. 2011); reduced probability of medical complications (Ljungberg et al. 2011; World Health Organization 2013); and community re-integration after injury (Jones and Gassaway 2016; World Health Organization 2013). Yet, rehabilitation as a field has not addressed or recognized participation in a peer disability community as transformative. This study is the first to shed light on disability community in the context of rehabilitation. Rather than examining rehabilitation as practice of only clinically trained (often able-bodied) medical professionals, this study takes an ethnographic approach to examine the sense of community-generated apprenticeship and rehabilitation among disabled people at Rancho. Rancho provides an interesting case study because the institution has long incorporated a sense of disability community in its ethos of rehabilitation.

In addition, this study examines intersecting dynamics of economic inequality in the United States, where about 65% of Americans between the ages of 18 to 64 with disabilities are unemployed. Those who are employed make an average of $10,000 less annually than non-disabled people. Not surprisingly, disabled people are 1.6 times more likely than non-disabled people to experience poverty (Kraus et al. 2018). As this ethnographic study centers on employees with SCI, it pays necessary attention to the dynamics of employment, volunteerism, and the intersections (Crenshaw 1989; Ervelles and Minear 2010; Moodley and Graham 2015; Nash 2008) of categories like disability and ethnicity.

One field that is well-situated to describe the structure of community is anthropology. While anthropologists have long theorized disability (e.g. Benedict 1934; Edgerton 1967; Frank 2000; Hanks and Hanks 1948; Murphy 2001; McDermott and Varenne 1995), few studies have outlined the everyday on-the-ground dynamics of communities centered around disability. One exception is studies among Deaf communities (e.g. Friedner 2015; Nakamura 2006 Senghas and Monaghan 2002), members of which typically reject disability as a label. Groups of intellectually and physically disabled folks have been less frequently researched. This gap leaves us without an understanding of the way disability is constituted through relationships among disabled people. This dissertation addresses this gap through analysis of the relationships and orientations physically disabled folks adopt in relation to one other and to impairment.

Initial research goals and (misguided) assumptions

At the outset of this project, I envisioned a dissertation that would describe the process of rehabilitating from inpatient to outpatient to well-adjusted disabled person at Rancho Los Amigos, where there is a thick sense of disability community. I thought that I would chart the process of coping with disability, from shattered pieces to a restructured sense of wholeness. The project had assumed that people who complete their inpatient rehabilitation at Rancho would come back, first as outpatients and then as community members. I had thought that in my two years of fieldwork that I would meet key consultants while they were inpatients and observe them as they returned to Rancho after being discharged and became fully integrated into the disability community.

The project did not materialize the way that I envisioned. It was hard to gain access to inpatients. The institution kept them constantly busy, and they had little down time to sit and conduct interviews. Furthermore, inpatients were often not in the hospital long enough to form deep relationships. Most insurances only subsidize two weeks of inpatient care. For patients to be granted the extensions that clinicians feel is required, a degree of paperwork and luck is required. Finally, there were not many inpatients whom I met who returned to Rancho to participate in the disability community. I surmise that patients were not ready to identify with disability in the timespan that I spent at the hospital. I was in the field for nearly two years, but the process of adjustment to the transition from able-bodied to disabled likely takes longer for many. Therefore, my research goals shifted to accommodate the therapeutic realities that I encountered at Rancho.

Methods

Research for the project consisted of participant observations carried out in phases over two and a half years. From September 2016 through July 2017, I formed connections with peer mentors and the hospital’s research department. This network was facilitated by weekly volunteering during which I assembled a Stroke Survival Guide for KnowBarriers. I learned about the daily flows of work and activity at the hospital and familiarized myself with staff, especially peer mentors. I also worked my way through the hospital’s bureaucracy, as volunteer clearance required training, paperwork, health checks, and countless visits to the human resources department. After obtaining permission from both Rancho's IRB and UCLA's IRB, I began fieldwork from September 2017 through April 2019. The study integrated (1) participant observation, (2) focal-person follows, (3) semi-structured interviews, (4) an adapted Community Integration Measure (McColl et al. 2001), (5) disability in action phenomenology (Howe 2011), and (6) field notes and audio recording when appropriate (see Appendix 1 for table of methods). Due to stringent rules of the Health Insurance Portability and Accountability Act (HIPPA), I did not video record at the hospital. It was also difficult, though not impossible, to audio record. When I did record, I obtained consent for each participant in the room.

Participant observation

Participant observation is a method of collecting data through observation of everyday life (Jorgensen 1989; Bernard 2006). I observed a number of settings at the hospital and participated in many of the activities. I kept ethnographic field notes (Emerson et al. 2011) each day that I spent at the hospital, paying attention to the structures of interactions between mentors, community members, patients, clinicians, and staff. Additionally, I gathered several audio recordings and photos in various settings.

Focal-person follows

To understand the work and activities of mentors and community members in greater depth, I conducted focal-person follows (Hawkes et al. 1991) of key disabled consultants. This entailed me following people throughout the course of their days at Rancho, taking field notes, collecting photographs, and making audio recordings when appropriate.

Semi-structured interviews

I conducted semi-structured interviews (Bernard 2006) with research participants who had SCIs and were peer mentors or Rancho community members. I identified interviewees during preliminary fieldwork and participant observation research. Interviews, which lasted between 30 and 120 minutes, covered participants' experiences with disability and rehabilitation. The interviews followed a general outline, but the format was open and conversational. Interviews were conducted in a quiet, private area around the hospital; nearly all were one-on-one; though, on two occasions, I conducted joint interviews with a participant with a SCI and his spouse.

Adapted community integration measure

Community integration metrics are typically used to measure a person's degree of rehabilitation and have been used in a number of studies to gain a sense of the rates of specific populations' rehabilitation (e.g. Rath et al. 2003; Shigekane 2007; Willer et al. 1993) and the efficacy of certain rehabilitative treatments (e.g. Cicerone et al. 2004; Goranson et al. 2003; Hanson et al. 2001; Kim and Colantonio 2010). The Community Integration Measure (CIM) developed by McColl et al. (2001) measures one's sense of integration into community with ten questions. Participants indicate how strongly they agree with the questions. I adapted the CIM by asking participants to imagine Rancho as the community to which I was referring and dropped several questions. I surveyed participants with whom I conducted semi-structured interviews. The results of this survey are explored in Chapter 3.

Disability in action phenomenology

Throughout data collection I reflected on my experiences in field notes. My position as a disabled ethnographer allowed me to phenomenologically reflect on *disability in action* (Howe 2011). Howe writes: "An ethnographer with an impairment is… in a unique position to document what could be called *disability action* - that is the impact of the impaired body on an otherwise 'ordinary' space" (2011, 287). My position as someone who moved into and out of

Rancho's alternative community space made me uniquely positioned to reflect on disability in action.

Ethnographic research was mostly conducted in spaces in which disability community was active around the hospital (see Appendix 2 for table of research methods). These included the following settings.

Inpatient-centric activities

(1) Occupational therapy (OT) and physical therapy (PT) appointments: Appointments for inpatients held in the OT/ PT gyms. There was usually at least one peer mentor stationed in the gym to provide their perspective to inpatients and clinicians. Bilingual Spanish/ English peer mentors might also be asked to serve as informal interpreters for Spanish-speaking patients.

(2) Peer mentor-patient visits: In-room visits from peer mentors to SCI inpatients during which mentors would check in on patients, explain their role in the hospital and offer to answer any questions.

(3) SCI Starting Out Classes: classes for SCI inpatients on several topics about living with SCI. The topics included autonomic dysreflexia (a condition associated with high-level SCIs), transportation, finances (information about how to apply for social security benefits), bowel care, bladder care, sexuality, pressure relief, psychological adjustment to SCI, introduction to KnowBarriers, community resources, and introduction to SCI. These classes were typically led by one clinician and one or two peer mentors. They were held in the activity room of the SCI inpatient unit every weekday before lunch. Inpatients were expected to attend each class before they were discharged.

(4) Events: Various events were staged for inpatients, including group outings to a nearby grocery store, or visits from local non-profit groups geared towards folks with SCIs.

Outpatient-centric activities and settings

(1) SCI support groups: Weekly support groups held for folks with SCI (one in English and one in Spanish) at the wellness center. Anyone was welcome to attend.

(2) Group OT and PT appointments: Weekly appointments for returning outpatients. These were held as groups, typically with one OT or PT and peer mentor. The classes would often cover one topic for the day, such as practicing going down stairs and curbs in a wheelchair.

(3) Recreational therapy (RT) activities: Various activities offered to outpatients and wellness center members, including art classes and outdoor activities.

(4) Wellness center: Gym on Rancho's campus where anyone could purchase an inexpensive monthly membership. The gym also offered art and exercise classes. This gym was constructed and opened during my fieldwork. There were many community members who worked out there, as well as Rancho staff. At least one peer mentor worked in the gym to chat with disabled community members and provide perspective and resources.

(5) SCI Transition Clinic: Medial clinic in which doctors saw SCI patients who were recently discharged. There was always a peer mentor stationed there to meet with patients after their appointments.

(6) Events: Activities centering around outpatients, such as a quadriplegic meet-up described in Chapter 3.

Peer mentor-centric activities

(1) Peer mentor training: Three four-hour training sessions for peer mentors. Trainings were led by two or three peer mentors with groups of about five future mentors. The trainings covered the KnowBarriers peer mentor manual.

(2) Staff meetings: Meetings for KnowBarriers staff held monthly.

(3) Staff events: Occasional outings for KnowBarriers staff, such a summer barbecue, birthday celebrations, and happy-hour gatherings.

Hospital-wide gatherings

(1) SCI Games: Annual event hosted by Rancho. The free event offered activities, such as wheelchair sports and a wheelchair obstacle course, vendors, and food. It was the largest Rancho event.

(2) Patient art shows: Occasional shows in which Rancho patients and community members displayed and sold the artwork they had produced in classes offered by the hospital, usually for free.

(3) Rancho farmers market: Weekly farmers market set up on Rancho campus around lunch time. Patients, staff, and community members would come to the farmers market for lunch and to socialize.

Outside events

(1) Los Angeles Abilities Expo: free convention for disabled folks where informational sessions were hosted, and medical supplies vendors showed off their technology. Though outside of Rancho, many community members attended.

(2) Disability Pride Festival: Annual event hosted in East Los Angeles. Anyone was welcome to come to the event, which included vendors, activities and a disability pride parade. Many Rancho community members attended.

Participants were initially recruited through connections formed with Rancho peer mentors and community members during preliminary fieldwork. Additional participants were recruited through the word-of-mouth technique. All study participants are referred to by pseudonyms of their choosing. By the end of ethnographic data collection, forty-three research participants had enrolled, twenty-three semi-structured interviews were conducted, about four hundred hours of participant observation and focal-person follows had been completed, and about twenty hours of audio recordings (outside of semi-structured interviews) had been captured.

Perpetual patients

I arrived early to a KnowBarriers staff meeting to find BJ, founder and Executive Director of KnowBarriers, preparing the projector for presentation. The other early comers greeted me and then returned to a conversation they had been having about the Dodgers. The room slowly filled with about forty peer mentors with a range of impairments. To kick off the meeting, BJ explained there would be a guest visit by Dr. Yang. As if on cue, Dr. Yang entered in his white coat and strode to the front of the room. He was there, he told the mentors, to introduce the hospital's new procedure to ask patients about their sexual orientation. He justified the institution's need to know this information by noting that sexual orientation might put people in certain risk categories about which doctors needed to know. Compelled to put this in different words, he said: "you don't expect a Chinese person to eat tortillas every day," a joke which elicited a chuckle from the room.

As he continued his presentation, he cautioned the peer mentors not to be "surprised if you are asked this question." It seemed unclear to me whether Dr. Yang was speaking to the staff as patients of Rancho or as employees of the hospital who needed to be made aware of the policy. Apparently, other people had the same confusion, as the doctor was soon harangued by questions about how peer mentors were supposed to ask these questions. One mentor asked, "When we go meet with a patient, won't we be able to tell their sexual orientation?" The doctor seemed unsure how to answer this question, at which point BJ interjected to clear up the mounting confusion. She told the workers, “we want you to know this so you can support the providers.”

Within the utterances of Dr. Yang and BJ, there is an interesting dynamic of stance and alignment. Dr. Yang’s caution not to be “surprised if *you* are asked this question,” suggests that he positions the peer mentors as patients. The underlying assumption of the doctor’s utterance is that many mentors are likely to be Rancho patients. This assumption is accurate; many of the mentors saw doctors at Rancho for issues related to their impairments. Nonetheless, the positioning seemed inappropriate in the context of a staff meeting. This discrepancy is perhaps why BJ presented a contrasting contextualization. The pronouns that she used may be expanded as such: “we [institutional higher-ups] want you [mentors] to know this so you can support the providers.” While Dr. Yang seems to align with peer mentors through a doctor-patient relationship, BJ aligns with the mentors through a supervisor-employee relationship. This confusion in stances and speaker frameworks continued to build.

Dr. Yang continued, “this could still cause you to feel uncomfortable, but please understand where we are coming from and share that with your friends who may be patients here.” Again, the doctor had positioned the peer mentors as patients, a linguistic move which resulted in another round of questioning from the mentors. One mentor asked, “so they get this information for data?” Finally, one PM, Kyle, said that he understood that the institution must ask this information, “but how does it fall back on us?” The framing of this question suggests that the speaker is positioning the clinicians as a separate entity from the “us” of disabled peer mentors. Notably, he is not adopting the doctor-patient framing that Dr. Yang had tried to build into the interaction.

While this question could have forced the doctor to shift his alignment, he instead provided an explanation that further muddied the participant framework. He answered “I just want to communicate with you so you are not caught off guard… You, as mentors, encounter things. People look up to you… Some of you have probably already been asked.” With that, the doctor seemed to think his reason for visiting was clear. His utterance suggests that he attempted to merge both frameworks - that of a doctor speaking to patients, and that of a supervisor speaking to his employees. The doctor could not seem to shift out of his framework of positioning the peer mentors as patients, even with the linguistic efforts by BJ and peer mentors to differentiate mentors from patients. The mentors were interpellated into this institutional role as recipients of care. Their professional roles were minimized, likely because of the intersection of their ability status and ethnic status. These shifts in alignment and participant frameworks are a microcosm of larger social processes linked to a long history of a strong disability community on the campus, as well as process of communal alignment, regimes of knowledge, and disability policies. This scene demonstrates that a focus on language and communication within this institution provides a rich and nuanced lens into the interplay of these forces.

Theoretical framing: Languaging the bodymind

"The vitality of language lies in its ability to limn the actual, imagined and possible lives of its speakers, readers, writers. Although its poise is sometimes in displacing experience it is not a substitute for it. It arcs toward the place where meaning may lie."

"We die. That may be the meaning of life. But we do language. That may be the measure of our lives."

Excerpts from Toni Morrison’s Nobel Lecture, 1993

Linguistic anthropology approaches language not only as a logical structure that is a sign vehicle for meaning (Chomsky 1965; de Saussure 1986) but also as a medium for “social action” (Ahearn 2001). Language performs action in the world and, in so doing, has the capacity to change the world (Austin 1962; Butler 1990; 2011; Heidegger 1977 [1949] Searle 1969). This dissertation draws on the idea that attending to the microprocesses of everyday communication reveals ways in which social forces and selves are constructed, reified and shifted (Garfinkel 1967; Goffman 1974, 1981; Ochs et al. 1996; Sacks 1992). The main units of interactional analysis are the participant framework (Goffman 1981) and stance (which I use interchangeably with alignment), a concept with “many genealogies… [that] focuses mainly on a speaker’s acts of self-positioning vis-à-vis interlocutors and objects in discourse, especially in face-to-face interaction” (Irvine 2009, 1). The most relevant aspects of stance for this dissertation are the ways interlocutors socially and affectively position themselves (e.g. alignment or disalignment) (DuBois 2007; M Goodwin 1998; 2006; Goffman 1981).

Through a focus on stance and participant frameworks, this dissertation builds a picture of social forces at play in rehabilitation among disabled folks at Rancho. I attend to the ways stance in everyday interaction is a means of structuring disability community. Anthropologists and sociolinguists have long been interested in the role that language plays in group-differentiation and social groups (e.g. Bloomfield 1927, Boas 1940, Gumperz 1968; Eckert and McConnell-Ginet 1992, Labov 1968, Sapir 1949). However, the field has faced recent critique for failing to incorporate the “body” as a sign vehicle of communication into analysis (Bucholtz and Hall 2016). Building on theories of multi-modal communication and group differentiation, this dissertation proposes a theory of “community” that is based on alignment between speakers and to impaired bodyminds. Despite the lack of scholarly consensus on community (Jansen 2019), studies of community tend to be valuable for providing a multifaceted approach to how people form social bonds, connections, entanglements, enmeshments, opposition and exclusion, particularly through a deep focus on contextualization. As Ortner explains, studies of community "portray the thickness of people's lives, the fact that people live in a world of relationships as well as a world of abstract forces and disembodied images" (1997, 64). By employing this framework, this study takes up the call from disability studies scholars to attend to 'disability culture' (Barnes and Mercer 2001; Peters 2000), which I reframe as disability *community*. There is considerable differentiation within and across disability communities. While community is a fluid concept, situated historically and culturally, I have opted for this term because it is the way groups of disabled folks often describe themselves.

In addition to linguistic anthropology, this dissertation is grounded in disability anthropology and theories of embodiment. I attend to the way interlocutors interact and act from the position of their habitus (Bourdieu 1977; 1990a; 1990b). Bourdieu's theoretical concept of habitus has been defined succinctly by Throop and Murphy (2012, 186) as "an internalized structure or set of structures… that determines how an individual acts in and reacts to the world" (see Bourdieu 1997; 1990a; 1990b). It is a mechanism through which social structures are embodied. Bourdieu has been critiqued for the homogeneity implied by *habitus*. While it is a useful theoretical concept for attending to the structural impact on consciousness, it is, as Throop and Murphy describe, "by no means the entire story" (2012, 201). They write:

> we feel that if we ever hope to develop an adequate account of social action it will be necessary to first ground anthropological research in systematic phenomenological investigations of those structures of consciousness that

> contribute to the patterning of experience, the attribution of meaning, and the cultural constitution of the life-world (2012, 201).

Along with Throop and Murphy, I argue for a descriptive orientation to consciousness inspired by phenomenology. I propose a theory of "disability habitus," referring to the behaviors and dispositions that people adopt in relation to their impaired bodyminds, especially in the context of rehabilitation. My use of 'habitus' borrows from Bourdieu's attention to structure but expands it to "investigat[e] the cultural patterning of subjective experience" (Throop and Murphy 2012, 200). While Bourdieu was concerned with the habitus as a concept to describe the structural impacts on individuals, the *disability habitus* attends to the embodied creative and generative forces through which individuals interact with and constitute their life-worlds. This term has been used by several scholars to examine the general orientation with which disabled people orient to their worlds (Björnsdóttir 2011; Ferrante 2008; Palacios et al. 2012), or as a promising theoretical concept to explore in future research (Simmons et al. 2008, 743). I depart from previous scholar by analyzing the disability habitus in everyday interactions, particularly between disabled folks. (2011).

This disability habitus is different from the rehabituation described by Lenore Manderson (2011), a process of adjusting to life in an altered bodymind following a corporeal rupture, because it depends on the alignments and relationships that disabled people form with each other. Responding to Wool, who found a "thin" sense of sociality among disabled veterans at Walter Reed, I propose a sense of "thick sociality" that exists at Rancho, and among many disabled communities. In his research on disabled war veterans in Turkey, Açıksöz (2012; 2020a; 2020b) points to the generative force of violence that not only disables and imprints bodies but opens up new forms of subjectivity. In a similar vein, I suggest that adopting a disability habitus, aligning with other disabled people and embracing an orientation to the disabled body is generative of a new form of community (I explore *community* in detail in Chapter 3). As Ralph explains, “wounds become the precondition for enabling social transformation” (2014, 121). Language is integral in this process of transformation and becoming (Capps and Ochs 1995; Hill 1995; Heidegger 1962; Mattingly 1998; 2010; 2014a; Ochs and Capps 2001; Ricoeur 1988).

Studies of interaction in institutional care settings have tended to focus on clinician interactions with ill or disabled patients (e.g. Clemente 2015; Garro 2000; 2003; Good et al. 2011; Hamilton 2003; Hamilton et al. 2006; Mattingly 1998; 2010; 2014b; Solomon et al. 2015). This leaves a conceptual gap in the research in which interaction among disabled and ill folks has not been fully explored. This dissertation provides a “participant-to-participant” – disabled peer-to-disabled peer – focus to build on this rich body of literature in medical and linguistic anthropology. The analysis demonstrates that interlocutors with spinal cord injuries socialize others into a disability habitus and provide a context for newly injured patients to imagine their future disabled selves.

Scholars attuned to conversation have argued that stigma is not an entity that exists, but rather something embedded in interactive structures and then lodged in bodyminds (Goffman 1963; Link et al 2001; Phelan et al 2008; Ochs 2015). Stigma is the co-occurrence of factors such as labeling, stereotyping, and discrimination (Link and Phelan 2001) and it functions to exploit and dominate, enforce norms, or segregate (Phelan et al. 2008). Building from this work, I argue that, rather than understanding impairment as a condition of biological lack, disability is better understood as an intersubjective and interactional process. This dissertation moves in concentric circles around the center point of the formation and reformation of disability habitus. I explore the history of variable instantiations of disability community at Rancho, the complex community that exists there in the present moment, and how disability habitus is differentially apprenticed, appropriated, and reconfigured among the patients and community member. It examines the top down (institutional and political) structuring of this community and habitus and the impact of different ‘generations’ of disability community on rehabilitation as an institutional and intersubjective force (read agency). This theoretical orientation is depicted in Figure 1.2, which shows the contours of the disability habitus. The image is an heuristic tool to help readers understand the levels at which I approach analysis. It appears in each chapter, with only the relevant levels of analysis highlighted. Of course, all factors in this sociality are interconnected and cannot necessarily be separated.

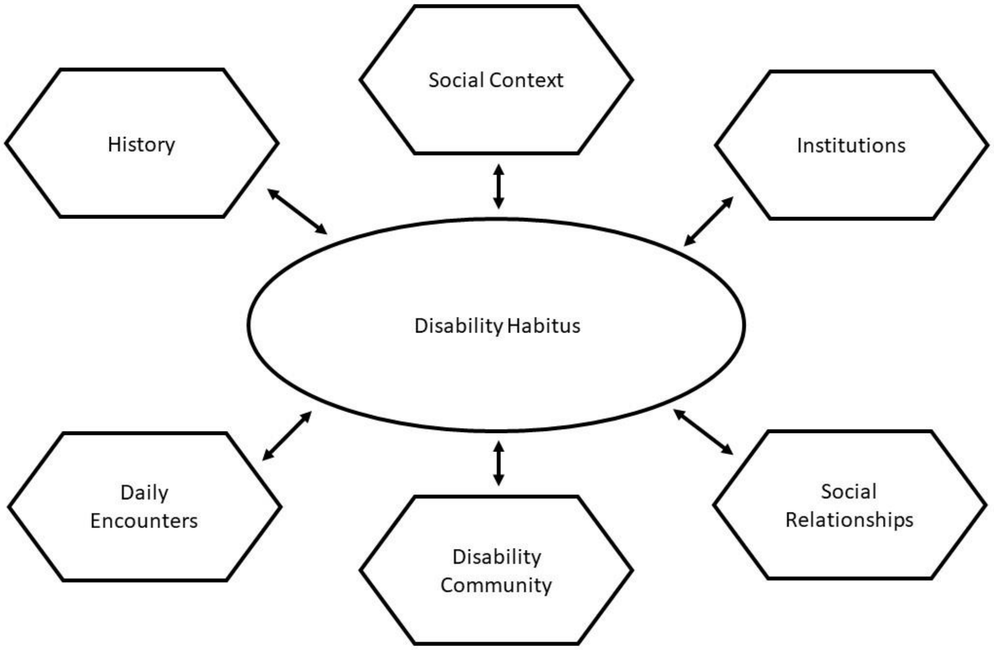

Figure 1.2: Contours of the disability habitus. The innermost circle represents the disability habitus, which interacts with micro-level forces, such as daily encounters between disabled folks, disability community (referring to Rancho’s community) and social relationships, in this case, the disabled folks who frequent the hospital. The disability habitus also influences and is influenced by macro-level structures, such as history (referring to the history of Rancho as a space of marginalization and subversive community), social context (the sociopolitical milieu of

ideologies about disability, political structures governing disability and the intersecting factors of ethnicity and class which impact the experience of disability.), and institutions, ranging from Rancho as a rehabilitation institution, to federal institutions, like the Social Security Administration.

Layout of the dissertation

While this dissertation deals with disability, it is not an exposé of suffering, nor is it a deep exploration of tragedy. Rather, it attends to the daily, often creative, linguistic practices of disabled people. The following chapters explore the historical, social and political dimensions of this topic. Chapter 2 examines Rancho's history as a poor farm in the 19th and 20th centuries. I employ a Foucauldian lens to contextualize the institution as a space of confinement (Foucault 1977; 1984; 1988) and exclusion (Agamben 1998) through which biopower is exercised. This chapter weaves the history of confinement, eugenics and rehabilitation together as threads in the modern (neoliberal) tapestry of Rancho. In dialogue with disability studies (e.g. Mitchell and Snyder 2015; Schweik 2009; Stiker 1982), I argue that a history of disenfranchisement paved the way for the present social context of rehabilitation at the hospital.

Chapter 3 explores the present sense of community at Rancho, which, I argue, is important because (1) disability communities have been theoretically taken for granted - assumed to exist, but not described in detail - especially in disability studies; (2) rehabilitation has failed to acknowledge the potential benefit of disability community. I explore theories of community in anthropology, socioligнuistics and rehabilitation, and I propose a theory of "thick sociality." I analyze recorded audio data from a quadriplegic meet-up to examine this community in situ.

Chapter 4 further outlines my theory of disability habitus and build on Hartblay's notion of "disability expertise" (2019). Through analysis of audio data, mostly from peer mentor trainings, this chapter explores some of the ways speakers linguistically orient to the impaired bodymind. It also examines moments in which disabled people are socialized into these orientations, thus expanding the disability habitus. These practices include ritualized SCI greetings, conversations about taboo topics, such as bowel, bladder and sexual functioning, and temporal orientations to an ordinary future.

Opening with an account of the near shut-down of Rancho by Los Angeles County in 2003, and the staged action by patients that kept the institution open, Chapter 5 centers around the question of agency. I propose a theory of complicit agency to describe how disabled interlocutors navigate structures of disenfranchisement related to intersecting categories of ability status, class and ethnicity. I examine alignment in excerpts of semi-structured interviews that demonstrate how speakers position themselves as moral actors, despite their inability to fulfill stereotypical (neoliberal) expectations of productivity.

Chapter 6 offers reflections on the research and suggestions for future directions of peer mentoring and rehabilitation. It concludes the dissertation by emphasizing the importance of attending to the under-researched social group of disabled laborers, as well as attending to the importance of historical conditions and consciousness in linguistic anthropological analysis.

CHAPTER TWO - A History of Rancho: From Poor Farm to Peer Mentors

Rancho Los Amigos National Rehabilitation Center timeline

1887 Plans for The Los Angeles County Poor Farm are introduced, and construction begins. It expands rapidly.

1888 The first set of inmates are moved from the Los Angeles County Hospital to the poor farm.

1907 The first psychiatric ward is built.

1920s The first infirmary is introduced. This is the beginning of institutional services for disabled, ill and indigent people who are not "able-bodied." Ultimately care for the people who are not able to work on the farm leads it to be not profitable enough.

1926 Occupational therapy is introduced to the institution and becomes essential for the philosophy of care, which values work opportunities for inmates (later "patients").

1932 The "Los Angeles County Poor Farm" becomes "Rancho Los Amigos" (Ranch of the Friends). This change is meant to shed the stigma of the poor farm and embody the intuitions commitment to medical care.

1944 Polio strikes Los Angeles County. Rancho is a leading institution for polio care. It eventually becomes the world's largest polio respiratory center (Fliedner 1990: 282).

1945 Following the end of WWII and the disbandment of Japanese American internment camps, Rancho housed 50 "elderly, single, ambulatory Japanese-American men from Manzinar [Internment Camp]" (Fliedner 1990: 224). The hospital instituted the 'Japanese Ward' for them until other accommodations were made.

1950s New departments are introduced, including Recreational Therapy, the Psychology Department, the Social Work Department, Vocational Rehabilitation Services. SCI Service is initiated; it becomes (and remains) the largest rehabilitation service.

1957 The last of the farm animals are sold off by this year; the remaining farmland is sold or tuned over to the county. This marks the complete phasing out of the farm and the transition to a chronic-disease hospital.

1959 Rancho is granted accreditation as a medical facility. Furthermore, by this date, the "mental wards" are gone and "care for the insane" is phased out. This marks the complete shift into a medical rehabilitation facility.

1965 President Lyndon Johnson signs Medicare and Medicaid (Medi-Cal in California) into law. This is an instrumental part of Rancho's shift away from convalescent care as people with disabilities and chronic conditions have more access to care.

1983 Rancho Los Amigos Foundation is formed. Its purpose is to solicit private donations for the hospital, especially for programming.

2002 The Los Angeles County Board of Supervisors votes to close Rancho Los Amigos because of high costs. Patients and staff protest.

2003 Disability rights advocates sue to save Rancho Los Amigos. They win and Rancho is kept open.

2020 Projected completion of "Rancho Rising," a program to build and expand rehabilitative services including a new wellness center, a remodel of some of the existing inpatient buildings, and a new outpatient building.

A Fire on the poor farm

On February 1, 2017, firefighters were called to a vacant building in Downey. They arrived to find flames ripping through the building, dancing through holes in the roof. The fire decimated an old structure owned by Rancho Los Amigos Rehabilitation Center (The Downey Patriot 2017). It was one of many buildings used in the early 1900s that the rehabilitation hospital largely abandoned by the 1980s. These buildings are relics of the hospital's past as a *poor farm*, before it transitioned into a medical rehabilitative facility. The buildings south of Imperial Highway (across the road from the modern rehabilitation center), used to house the inmates of the Los Angeles County Poor Farm,[1] established in 1888 by the L.A. County Board of Supervisors (Fliedner 1990; HABS CA-2800). The public institution, and others like it, were intended to provide a place for the county's elderly, ill, disabled and destitute residents (Katz 1996). Inhabitants were called "inmates," and those who were able-bodied enough to labor were required to work on the farm, till the land, pluck citrus fruits from the orchard, milk cows, cook food, clean the facilities, and keep up the farm in return for their housing. Furthermore, the farm

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[1] Fliedner notes that the institution was named the Los Angeles County Farm, while the Historic American Building Society report refers to it as the Los Angeles County Poor Farm. I have decided to use the former name, as this is less euphemistic than the latter.

had a self-sustaining community. It provided its own power, produced its own dairy (and provided the excess to the county), had its own source of water, and even had a refrigerated morgue where dead inmate's bodies would be preserved and examined before being buried in the campus graveyard. Now many of the buildings sit across the road from the modern-day hospital, vacant and decaying.

Figure 2.1: Vacant building on south Rancho campus ablaze, February 2, 2017. In the foreground, a firefighter attempts to attach a hose from firetruck to fire hydrant. In background flames and black smoke emanate from hole burned through roof of abandoned building. Photo credit: Downey Fire Department.

This chapter outlines the history of Rancho to draw a temporal connection between its past as a poor farm and its present, as a public institution where disability community (as well as undesirable attitudes towards disability, like paternalism) thrive. These field notes from one of my early visits outline what this sense of community looks like today.

January 5th, 2017

> Rancho feels like an alternate universe. When I first started coming here, I always caught myself staring at the busy inpatients and outpatients with obvious disabilities, as they made their way from one end of campus to the other. Today I watched people from all different walks of life who live disability differently: the man in the clunky wheelchair, pushed by his mother; the woman with high heels and a wheelchair backrest tied tight like a corset, who pushed so quickly that I could not read the stickers adorning her chair; the mysterious man in the cafeteria who caught me mid-gaze and warned me "enjoy what you have because, before you know it, it's gone"; the woman with long hair and a long skirt that quivered each time she set down her 4-pronged cane, and who looked as if each step with her half-paralyzed body required major concentration. At first, I was not used to seeing disability everywhere I turned my head. But as I continue to visit, I realize that we crips share our own secret language: a head-nod exchanged across the hall to a stroke survivor who could not utter words; a "good morning" to the woman racing by me with the corset-wheelchair; a "hello" to a man using a walker with heavy, lumbering steps.

This sense of community is historically grounded. It is influenced by historical context, for instance injured miners in the late 1800's; elderly Japanese men from a newly closed internment camp in the 1940's following the end of WWII; post-polio patients in iron lungs in the 1940's and 1950's; Vietnam Veterans in the 1960's; the increase of stroke patients as people have become more likely to survive strokes, especially since the 1960's (American Heart Association); etc. The vibrant community has always centered around disability.

In this chapter, I explore the history that grounds this community. I draw on post-structural theory (i.e. Foucault 1977; 1984; 1988; 1990), political science (Agamben 1998; 2004) and disability studies histories (e.g. Baynton 2013; Longmore 2003; Schweik 2009, Snyder and Mitchell 2006) to explain how the poor farm existed as a space in which biopower was exerted and abject bodies were excluded from mainstream society. Furthermore, I examine histories of the hospital, many of which paint a rosy, idyllic picture of the poor farm, to argue that a sense of disability community has always been an integral part of the institution. I must read against the grain of these optimistic histories, which follow the usual narratives of history that exclude the voices of disabled people and focus on a medicalized picture of impairment that touts the scientific advancements of generally able-bodied, white men in positions of institutional privilege and control (Longmore 2003). As the voices of the disabled, ill and indigent populations that have occupied Rancho for over a century are not generally highlighted in archival sources, I imagine a community that centered around impairment and I shed light on the strong forms of community that contribute to the hospital's sociality now.

Origins of the idyllic poor farm and the moral fear of disability

In her groundbreaking disability history, Schweik discusses the 'ugly laws' of the second half of the nineteenth century and early twentieth century: laws in many urban centers of the United States, such as San Francisco, Denver, Chicago, and Pittsburgh, that made it illegal for beggars, homeless people, those with visible disabilities, and other unseemly "displays of disease, maiming, and deformity" (Schweik, 2009, 17) to be in public places. Ugly laws, typically referred to in municipal codes as unsightly beggar ordinances, existed to expel indigent, ill, disabled and other pathologized groups of people out of the public gaze. They gained popularity in the second half of the nineteenth century, when industrialization and post-Civil War migration brought increasing numbers of people to urban centers. For instance, the first ugly law Schweik found record of was passed in San Francisco in 1867 in the wake of the gold rush, which witnessed a flow of immigrants, many of whom moving because they were down on their luck and longed for economic prosperity. The immigration of people with limited resources, the flooding of urban centers and limited job prospects coincided with an increase in homelessness and begging, as well as increase in middle class anxieties about 'unsightliness.' Contemporary measures, like the mass quarantine of Chinese Districts to "control infectious disease," (Schweik 2009, 28) and "ugly laws may be understood as an interlocked attempt to map and contain deviance" (Schweik 2009, 28).

Theoretically, Schweik draws a connection between these ugly laws (and the temporal thread that manifests now as stigma of disability) as a response to the new "discipline of the body" (2009, 31), a kind of polite society of the masses. As 'unsightly' and 'unseemly' loafers were kicked off the streets, where did they go? Schweik claims that the poor farms, poor houses, and the related almshouses grew in popularity along with such laws according to the Foucaudlian logic of biopower - as a mechanism of population and bodily control (Foucault 1990). She writes:

> With an almshouse in place, street-cleaning could proceed, justified - when proper - as caretaking… [The] unsightly beggar ordinances, the history of institutionalization and incarceration in poorhouses, and the modern independent living movement are inextricably linked… Traditional poor relief disguised its hostility toward those whom San Francisco named the infirm and the unsightly, under the mask of charity (Schweik 2009, 26-27).

In this account, institutions for indigent and disabled people are the result, - the underbelly - of the removal of their abjection from polite public society. It was in historical moment in which the idea for a poor farm in the L.A. region came to fruition. In 1887, the Los Angeles County Board of Supervisors purchased land intended for the county's poor farm where elderly, ill, disabled and destitute residents in need of care. It would become a space in which they could be housed and employed. In 1888, construction on the Los Angeles County Poor Farm began. The poor farm model was originally a British form of social welfare and was popularized during the Industrial Revolution. Poorhouses and poor farms were developed to house a city's indigent, disabled and elderly population, individuals deemed most in need of care (Katz 1996). One historical account of Rancho Los Amigos explains:

> Early poorhouses served as the origins of the modern American welfare system and followed the English tradition of care, jointly serving as a rehabilitation center and correctional institution. These establishments did not distinguish between individuals suffering from poverty and criminal behavior (HABS CA-2800, 17).

In the second half of the nineteenth century and continuing into the twentieth century, the poor farm "system was widely supported, as it was believed that such housing could reform people and heal them of bad behavior, which caused the 'afflictions' of poverty and criminality" (HABS CA-2800: 17). The Los Angeles County Poor Farm was built to meet the needs of the booming population in Southern California. As a poor farm, the institution was particularly profitable. Inmates worked on the citrus and dairy farm, which produced more than enough capital to sustain the poor farm's operations. But the poorhouse model grew less popular in the

United States and the population of Southern California expanded, as did the need for health care.

In a historical account of Rancho, commissioned by the institution to coincide with the centennial celebration in 1988, Fliedner outlines a similar process to the one Schweik describes with the codifying of ugly laws and the underlying logic of middle-class anxiety forcing blighted people into institutions. In the second half of the nineteenth century, Los Angeles County experienced a large population boom, due in part to the gold rush, but also as urban centers expanded and drew immigrants with hopes of prosperity (see Figure 2.2). Los Angeles County contracted with the Sisters of Charity to fund the county's first hospital (Fliedner 1990, 10). Increasing urbanization and the growth of the railroad system brought larger amounts of people to the county through the end of the century. Eventually, the public hospital ran out of space for patients. To house long term indigents (mostly permanently disabled former miners, immigrants from other countries and states) and free up space for other ailing citizens, the county decided to buy a parcel of land in 1887 in Downey, then agricultural lands outside of the city of Los Angeles.[2] The 124.4 acre tract of land was built and established as the Los Angeles County Poor Farm,[3] tilled and cared for by the indigent, disabled and ill people who were 'functional' enough to perform manual labor. Since being built in 1888, the institution has undergone a continual process of expansion and transformation. Through a Foucauldian lens, this care has been an exertion of biopower, a means of control of the unruly bodyminds which do not fit the ideal (read

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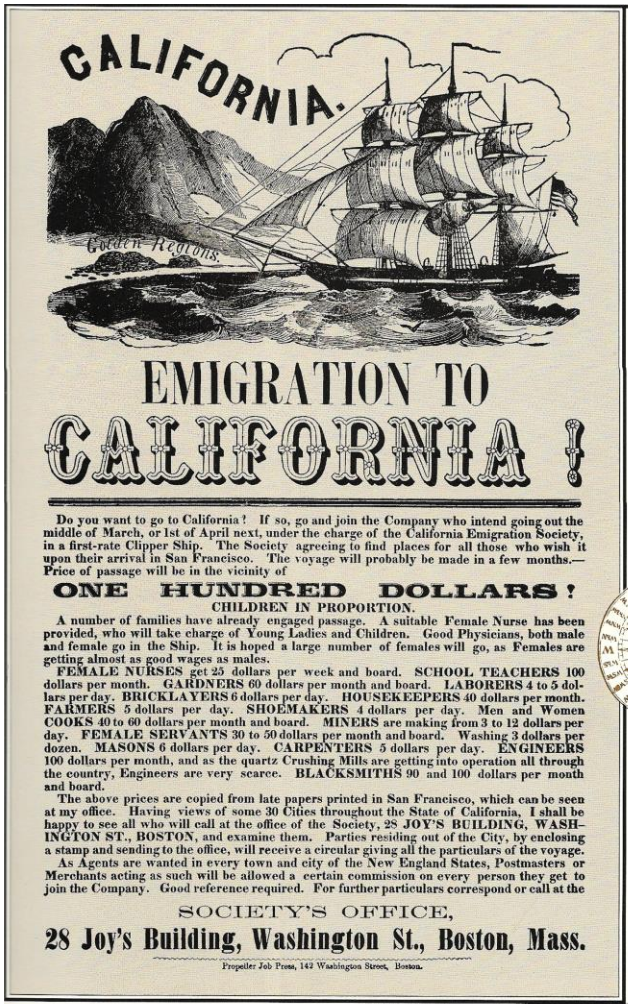
[2] Prior to Spanish colonization, Downey was likely inhabited by members of the Tongva Native American group (McCawley 1996). The area was settled and colonized by the Spanish from 1769 - 1824, then by Mexico, until 1948 when California was annexed to the United States (Habs CA-2800).

[3] Fliedner notes that the LA Board of Supervisors reffered to the farm interchangeably as the "Hospital Farm," "Alms House," and "Poor Farm" (Flidner 1990, 444).

white, able-bodied, able-minded, middle class) mold, and an “indispensable” concept for critical disability theory (Tremain 2005, 7). The concept of biopower describes a form of control which arose in the second half of the eighteenth century (Foucault 1990). This interlocking system of surveilling populations to “create data about normal bodies” and self-disciplining to achieve normalcy (Kupers 2003, 5), is embedded in the rise of scientific and medical institutions, rehabilitation centers and poor farms among them (Foucault 1977; 1988; 1990; Schweik 2009; Tremain 2005). Many of the people who found themselves confined within the walls and fields of the poor farm were seen as ethnic outsiders, thus blurring the boundaries between disabled bodyminds, race, and perceived criminality to which scholars working at the intersections of critical race theory and disability studies have pointed (Bell 2017; Erevelles 2011; Erevelles and Minear 2010; Lovern 2008; Puar 2017; Schalk 2018).



EMIGRATION TO

CALIFORNIA !

Do you want to go to California ? If so, go and join the Company who intend going out the middle of March, or 1st of April next, under the charge of the California Emigration Society, in a first-rate Clipper Ship. The Society agreeing to find places for all those who wish it upon their arrival in San Francisco. The voyage will probably be made in a few months.—Price of passage will be in the vicinity of

ONE HUNDRED DOLLARS !

CHILDREN IN PROPORTION.

A number of families have already engaged passage. A suitable Female Nurse has been provided, who will take charge of Young Ladies and Children. Good Physicians, both male and female go in the Ship. It is hoped a large number of females will go, as Females are getting almost as good wages as males.

FEMALE NURSES get 25 dollars per week and board. **SCHOOL TEACHERS** 100 dollars per month. **GARDNERS** 60 dollars per month and board. **LABORERS** 4 to 5 dollars per day. **BRICKLAYERS** 6 dollars per day. **HOUSEKEEPERS** 40 dollars per month. **FARMERS** 5 dollars per day. **SHOEMAKERS** 4 dollars per day. Men and Women **COOKS** 40 to 60 dollars per month and board. **MINERS** are making from 3 to 12 dollars per day. **FEMALE SERVANTS** 30 to 50 dollars per month and board. Washing 3 dollars per dozen. **MASONS** 6 dollars per day. **CARPENTERS** 5 dollars per day. **ENGINEERS** 100 dollars per month, and as the quartz Crushing Mills are getting into operation all through the country, Engineers are very scarce. **BLACKSMITHS** 90 and 100 dollars per month and board.

The above prices are copied from late papers printed in San Francisco, which can be seen at my office. Having views of some 30 Cities throughout the State of California, I shall be happy to see all who will call at the office of the Society, 28 **JOY'S BUILDING, WASHINGTON ST., BOSTON**, and examine them. Parties residing out of the City, by enclosing a stamp and sending to the office, will receive a circular giving all the particulars of the voyage.

As Agents are wanted in every town and city of the New England States, Postmasters or Merchants acting as such will be allowed a certain commission on every person they get to join the Company. Good reference required. For further particulars correspond or call at the

SOCIETY'S OFFICE,

28 Joy's Building, Washington St., Boston, Mass.

Propeller Job Press, 142 Washington Street, Boston.

Figure 2.2: California Emigration Society poster. The poster is an advertisement to pay for a trip to emigrate to California. The advertisement, with a sketched ship on the top, outlines the weekly wages for positions that one could expect to receive in California. Image from Fliedner 1990.

Yet, Fliedner's commissioned account of Rancho's one hundred years does not read biopower in the accounts that structure her book. Rather, Fliedner focuses on the idyllic setting of the farm, the architectural features, and the main actors (all, presumably, white able-bodied men) who made the decisions about how the farm should progress. Fliedner includes the following quote from an unnamed visitor to the farm 1898:

> A couple of miles west of the town of Downey, on the line of the Terminal Railways, is located the County Farm, spoken of by philanthropists from every

> part of the United States who have visited this beautiful institution, and they say without exception that Los Angeles County has the most beautiful, well managed and cheerful home for those that are unfortunate, of any country on earth. It is a revelation to see the high regard shown the poor and the sick at this home. The people of the farm speak in highest praise of the treatment received from the management and find much enjoyment among the abundance of flowers and beneath the immense shade trees that cover the beautiful lawns. The charming court is even a greater source of enjoyment, with its playing fountain, roses and vines (Unidentified writer in Fliedner 1990, 40).

Such a rosy picture of the charitable ideologies that circulated around notions of poor farms is not uncommon for the time. It is significant that Fliedner leaves the author unnamed, with no explanation of who this person is. Such a choice implies that this was simply the logical and acceptable opinion of the time. Fliedner's account of Rancho's history that emphasizes the charitable angle conflicts with Schweik's perspective, along with most disability studies, which reads charity through a suspicious gaze. In her explanation of ugly laws and the institutions into which the ugly laws force disabled and indigent people, Schweik claims that what is purported to be philanthropic is a project of segregation and marginalization. This is a common critique of charity from disability studies, as charities which 'serve' a 'needy' population tend to exploit and enforce models of disabled people as dependent, childlike, suffering and in need of help from able-bodied outsiders. In Longmore's analysis of campaigns for disability-centric organizations, he notes that the selection of 'poster children' reflect the public attachment to images of disability as both sweet and pathetic. He explains that (typically white, somewhat attractive) disabled poster children symbolized the paternalism that kept disability charity organizations afloat (Longmore 2013). In the campaigns that he describes, disability was portrayed as tragedy and these campaigns tugged at the collective heartstrings of the public to elicit emotions that would promote philanthropic sentiment.

Given the tone of the archival resources to which I have access, it is necessary to contextualize Rancho's history within the rise of biopower and the means of control that have been associated with medical and criminal institutions; the poor farm is a blend of both. In the following section, I relate this history to the genealogy of madness that Foucault outlines.

From lepers to indigents: Foucault on abnormality and confinement

To understand how such a space of marginalization exists, a historical account of institutions for disabled people is required. Foucault provides an account of institutions related to the poorhouse during the Classical Age. In *Madness and Civilization* (Foucault 1988), he argues that institutions of confinement, such as hospitals and prisons, arose by the seventeenth century in Europe to fulfill the society's desire for expulsion and exclusion that the eradication of leprosy in the Western world had eliminated. Prior to the Classical Age, lepers were expelled from their communities and quarantined together in lazar houses. Foucault draws attention to the ways in which leper colonies reinforced beliefs in segregation and sacred distance. This exile had a sacred metaphysical quality, with the exclusion of a leper leading to his eternal salvation. When the problem of leprosy vanished, the social need to separate and contain did not:

> What doubtless remained longer than leprosy, and would persist when the lazar houses had been empty for years, were the values and images attached to the figure of the leper as well as the meaning of his exclusions, the social importance of that insistent and fearful figure which was not driven off without first being inscribed within a sacred circle (Foucault 1988: 6)

Foucault sees institutions of confinement as a kind of modern lazar house. In institutions like the Hôpital général de Paris,[4] madmen, invalids,[5] the poor and the unemployed were housed. Foucault argues that this institution did not exist primarily to care for people; rather it existed to confine the poor. The mission of the hospital was not simply a pragmatic one (to house the poor); it was also moral. Inmates of the hospital were laborers. They were producers of goods, the selling of which could fund the upkeep of the institution. Through hard work, the inmates improved their purportedly weak morals: “Labor in the houses of confinement thus assumed its ethical meaning: since sloth had become the absolute form of rebellion, the idle would be forced to work, in the endless leisure of a labor without utility or profit” (Foucault 1988: 57). Thus, the moral demand for confinement and labor replaced the spiritual light under which lazar houses were conceived as spaces of both expulsion and redemption. Inmates had their chance at redemption through labor.

This history lays the groundwork for Foucault’s thesis of the scientific discovery of madness: madness began to appear in these emerging institutional spaces. Madmen fit into the category of those who should be confined - excluded for the sake of society and for their own benefit. Therefore, the historical moment of confinement constructed madness as a problem. Foucault’s historical account hints at but does not make the connection between institutions of confinement and disability (or invalidity, perhaps more aptly). In these spaces, disability,

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[4] Created in 1656, the Hôpital général de Paris was an attempt by Parisian elites to solve the problem of vagrancy and relief for the poor. It was a mode of confinement for homeless and poor people (McHugh 2001).

[5] The Oxford English Dictionary defines *invalid* as an infirm or sickly person. The earliest usage cited is 1709. It is related to the term *invalides*, meaning someone who is sick, old, and or disabled. The term *invalid* is no longer a preferred term for disability, but I use it here to give a sense of the way disability was viewed and discursively constructed. The label *invalid* lends itself to the breakdown of semantic boundaries between impairment, illness and old age.

poverty, and beggary were conflated into one mass social problem. In an ironic twist, the modern world that seeks to contain madness is the same world that brings madness into being.

In this chapter, I make a parallel argument – the modern structure of disability, particularly in the United States, is built on an historical framework of institutionalization. This structure, whereby disabled people are sequestered in institutions that provide 'care,' is a structure of control. It relies upon the same metaphysical drive to segregate, expel and redeem lepers, upon which Foucault builds his thesis of madness. Within this institutional confinement, 'disability' as a scientific object emerges and subsumes the gaze on the bodymind. Disability becomes an object that can be rehabilitated, minimized and cured. In the remainder of this chapter, I explore institutions through which disability is produced, rehabilitated and governed. I focus on the historical transformation of Rancho Los Amigos from a poor farm to a rehabilitation facility. I explore the question: Why is there a need for institutions that confine disabled people (along with the poor, the elderly and the mad people that Foucault mentions) (see Figure 2.3)? I engage theories of confinement (Agamben 1998; 2004; Biehl 2005; Foucault 1977; 1988) and suggest that they have missed an essential aspect of spaces of exclusion. While Foucault and Agamben describe the systems of power by which people are justifiably cast out of society, they do not attend to the creative forces of community-making that emerge. The image below and the remainder of the chapter, highlight the disability community which enters the feedback loop of power through which both exclusion and subversive inclusion are structured.

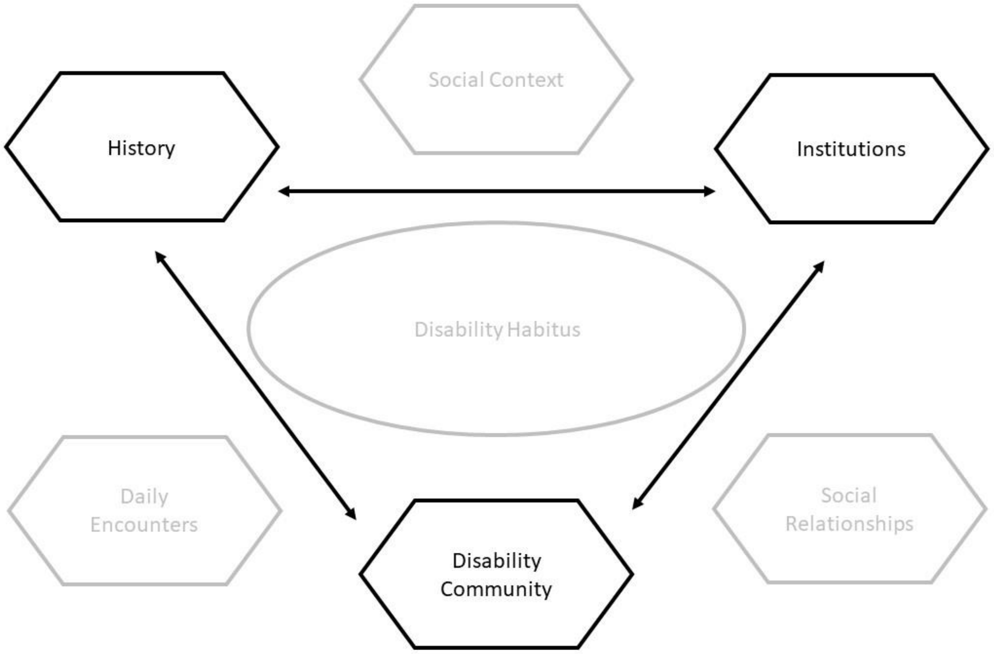

Figure 2.3: Contours of institutional exclusion. The image demonstrates the main themes this chapter explores: history; institutions; and disability community, which interact with each other.

The history of marginal spaces

I propose that poorhouses are an evolution of Foucault's 'houses of confinement.' Poorhouses were "the cutting edge of poor relief policy in the late eighteenth and early nineteenth centuries" (Katz 1996: 3). Katz explains that local governments in the U.S., operating under the assumption that laziness was the cause of pauperism, opened poorhouses to provide relief for rapidly growing poverty and to encourage able-bodied Americans to maintain a strong work ethic. By shutting away inmates from friends and families, poorhouses were meant to deter people from sloth. Like institutions of confinement, poorhouses both provided shelter to the most vulnerable members of society and provided a space of exclusion that kept them segregated. Katz explains that the poorhouse model soon developed into that of the poor farm – a facility that operated a farm on which inmates were required to work. The moral mission of the poor farm is not far from the ethic of rehabilitation with which we are familiar today. Katz writes: "The new institutions all rested on the optimistic assumptions about the possibilities of reform, rehabilitation, and education. Their sponsors believed that institutions could improve society through their impact on individual personalities" (1996: 11). Able-bodied, economically destitute people were perceived as undeserving of relief in a poorhouse or poor farm. Conversely, the 'impotent poor' were understood to be truly in need of the protection that such institutions provided.

Eventually, the poor farm system of welfare began to fade out of popularity in the late nineteenth century for most of the country (Katz 1996), but not until the first half of the twentieth century for Rancho. As the poor farm model fell out of fashion, the Los Angeles County Poor Farm made the slow transition into a rehabilitation hospital for people with disabilities. As the institution expanded and filled more beds with patients who were not "able-bodied" enough to work the farm, the poor farm model proved less and less sustainable. In 1932, the poor farm changed its name to "Rancho Los Amigos" (Rancho of the Friends). This change was meant to shed the stigma of the poor farm and embody the intuitions commitment to medical care. Yet, Rancho continued to carry out the mission of restoring order to individuals and society by transforming the inmates (later the patients) into morally upright citizens through work. As the farm began to be abandoned (a process completed by the late 1950's), work was central to the ethos of rehabilitation, thanks to the occupational therapy department, which was formally established in 1926. Throughout the 1930's and likely the 1940's, occupational therapists trained patients in rug-making, leatherwork and carpentry, and they made much of the equipment, furniture, linen and shelter in the institution. Polio patients worked in the rehabilitation shop, where they made watches, ceramics and other crafts. The hospital still employs outpatients who have successfully completed rehabilitation as peer mentors (explored in detail in later chapters) and employees in the hospital gift shop, where patient's handmade crafts are sold. It also proudly displays patients' and disabled community members' artwork throughout the halls.

As rehabilitation became a recognized medical practice, the goal has been to "restore" its patients to an able-bodied functionality (Linker 2011; Verville 2009). The field of rehabilitation grew immensely following major wars -- WWI, WWII, the Korean War, the Vietnam War -- during which soldiers returned from combat with a plethora of injuries. A major goal of rehabilitation was to enhance the ability of these newly disabled veterans to 'function' in society. Rehabilitation accrued an underlying moral value of re-instituting a laboring (thus docile) population. As Foucauldian disability historian Stiker (1999: 128) explains:

> [R]ehabilitation marks the appearance of a culture that attempts to complete the act of identification, of making identical. This act will cause the disabled to disappear and with them all that is lacking, in order to assimilate them, drown them, dissolve them in the greater and single social whole.

Rancho administrators viewed (and continue to view) labor as therapeutic. The laboring bodymind at the poor farm and later the rehabilitation facility was viewed as an improving bodymind. One superintendent of the L. A. County Poor Farm, William Harriman, "insisted that the patients work towards their own physical improvement" through the jobs they were assigned, like working on the farm or in the greenhouse, activities that "were also intended as physical therapy, by providing the patients with fresh air, sunshine and independence" (HABS CA-2800: 11).

Rehabilitation to labor resonates with Foucault's analysis (1977) of the hospital not as a place to die but as a therapeutic operation wherein bodies become the focus of power. Science and the state push for bodies that are trained, manipulated, shaped and skilled. Governmentality is exercised through technologies that motivate an individual’s sense of control over his bodymind. In the poor farm (and later the rehabilitation center), individuals become morally valid as they gain control over their bodies – when their bodies are laboring bodies, or when their bodies are trained according to the ethos of physical and occupational therapy. This disciplinary power trains “the moving, confused, useless multitudes of bodies” (Foucault 1984: 188). Though the poor farm model eventually died out, institutions that held disabled people, including Rancho, remained spaces of segregation and bodily control:

> [T]he vanishing of the poor-farm… also reflects an ideological change: paradoxically... the mechanisms for 'altering' the 'diseased, maimed, and deformed' multiply and disperse across a society fully invested in the seemingly kindler and gentler medical disciplining of disability... In the contemporaneous development of state institutions for the 'crippled,' 'feeble-minded,' 'insane,' and later the 'epileptic,' those spaces of exclusion, American society was inventing other available mechanisms... for segregating disability (Schweik 2009, 67).

Rancho’s past resonates with Linker’s (2011) account of rehabilitation as: “a way to restore social order after the chaos of war by (re)making men into producers of capital” (2011, 4). After disabled WWI and WWII soldiers returned home, the driving force of rehabilitation was the remaking of men whose masculinity had been damaged (Ibid). They would be able to become ‘men’ again by returning to work, overcoming their disabilities with grit and a drive for independence, and reinforcing American hegemonic masculine adoration of hard work. Once successfully remade as men, they would be able to reintegrate into normal society. Here rehabilitation is a process whereby men with disabilities were transformed into unmarked citizens. This moral force influenced Rancho, as it did the rest of the country. The hospital continued to expand after WWII, as more funding and interest were invested in the project of rehabilitation nationally.

Linker's history of rehabilitation and the history of Rancho converge and diverge at various points. I agree that, in one sense, rehabilitation is a process through which injuries are minimized, so that normalcy can be returned to life that has suddenly been struck by disability. Yet, this process is only part of the picture. Paralleling Foucault's history of madness, I trace the history of rehabilitation back to the institutions of confinement into which disabled, mentally ill, criminals and poor people all seemed to fit. Rancho's history may not coincide with the history of Walter Reed military hospital that emerged as the preeminent rehabilitation center in the wake of the world wars and a focus of Linker's account. Patients of Walter Reed were distinct from the inmates (and later patients) of poorhouses and poor farms. The patients at Walter Reed had emerged from normalcy and were now trying to cope with disabilities that threatened their established adult lives. Alternatively, inmates of poorhouses and farms emerged largely from the margins of society. These institutions were vessels through which such persons could be further separated from and not returned to the norm.

This dissertation provides an unwritten history of rehabilitation. The rehabilitation that emerged at Walter Reed may differ from rehabilitation that emerged at Rancho Los Amigos, which traces its roots to the poor farm model. Many inhabitants at the hospital were long-term residents. Even after the L. A. County Poor Farm had begun the transition to a rehabilitative medical facility, it provided a home to those with disabilities who had nowhere else to turn – becoming a kind of convalescent home. In the polio epidemic of Los Angeles that began in 1944, Rancho became a premier facility for research and care of polio patients. It was not unusual for people who required an iron lung to live at the hospital (see Figure 2.4). Additionally, Frank's

(Ibid) account of Diane, a congenital quadruple amputee, notes that Diane lived at Rancho for a stint during the Vietnam War. Ultimately, there were so many beds occupied by veterans that Diane had to be transferred. Diane had turned to Rancho, because she could not live at home anymore due to issues with her parents. At the hospital, she found a vibrant community of many other disabled peers with whom she would get into mischief (Frank 2001).

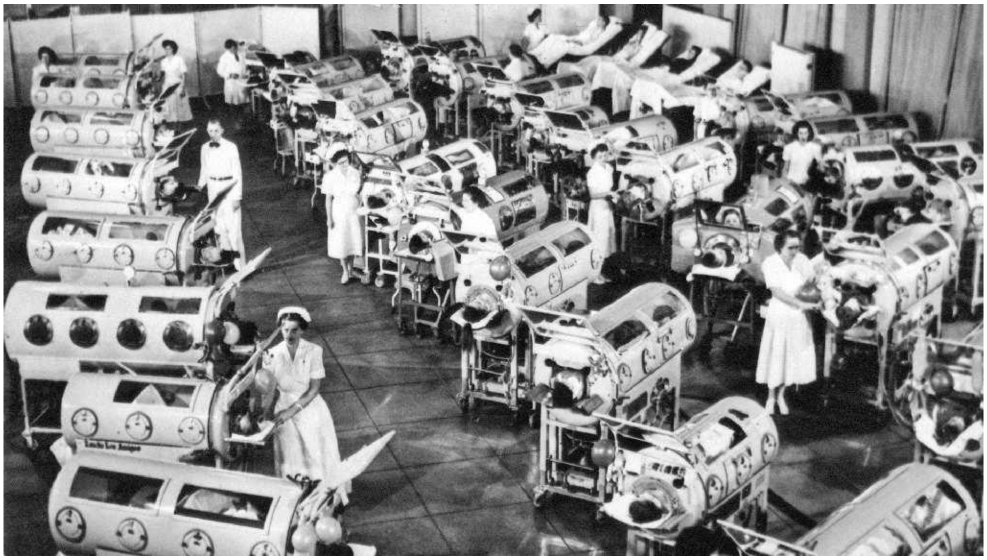

Figure 2.4: Staging of Rancho's iron lung machines and patients. Patients were staged for a one of several March of Dimes 'trailers' filmed at the hospital to be shown before films to raise funds for polio research and services. The photo was likely taken in the 1950's. It is a black and white image that depicts four rows of patients in iron lungs in a large space. Several nurses tend to individual patients.

An interesting exploration of an institution that functions as a collection of marginalized people is João Biehl's work on Vita (2005) in Brazil. Vita began as a drug rehabilitation center, but, increasingly, homeless people were dumped there. In Biehl's description, Vita is an institutional collection of those people who are the most liminal in Brazilian society, people in some of the most destitute situations imaginable. The residents of Vita have an amalgamation of issues, such as homelessness, poverty, disease, and a diagnosis of mental illness. Biehl refers to Vita as an 'end point', a place where people are 'left to die,' 'a dump site,' 'the end-station on the road of poverty.' It is one of many institutions that arose in Brazil in a neoliberal milieu in which people for whom no one wanted to care were abandoned. The process of letting people die in these institutions brought in profits for the operators of the institution. It is a space of social and eventual biological death for the liminal members of society, a *zone of social abandonment* (Biehl 2005). A similar notion of abandonment is also described in the work of Agamben (explored in the next section).

While I do not consider Rancho to be a zone of social abandonment where people are left to die, there is a quality that resonates with the place of marginality that Biehl exposes in his ethnography. To describe the state of the occupants of Vita, he uses the theoretical notion of “ex-humans.” While reluctant to use this term, he does so to "try to express the difficult truth that these persons have been de facto terminally excluded from what counts as reality” (2005: 52). In other words, their in-humanity justifies the abandonment they experience as they wait for death in Vita. Both Vita and Rancho are spaces that collect people who are somehow excluded from society. Furthermore, these spaces of collection fit into larger systems of profit. Historically, the L. A. County Poor Farm was a profitable institution. The similarities between the poor farm model, especially the connection to Foucault’s notion of confinement, Agamben’s concept of state of exception, and Biehl’s notion of a zone of social abandonment are striking. Biehl’s ethnography does not explain why these spaces of exclusion are carved out. Foucault might claim that the drive for exclusion is a vestige of the ritual separation that occurred in lazar houses. But this still does not postulate an origin of the desire to exclude. In the next section, I turn to theorists who might help explain why people with disabilities, illness, and poverty are so often pushed into zones of exclusion.

A violent expulsion

One way to shed light on the way societies carve out marginal zones is to turn to a political explanation. Agamben provides one such theoretical model with his conception of the *state of exception*. In *Homo Sacer* (1998), Agamben draws on Greek political philosophy to describe the difference between zoē, "which expressed the simple fact of living common to all living beings" and *bios*, "which indicated the form or way of living proper to an individual or group" (1998: 9). According to this distinction, *bios* is legitimized social life; for the Greeks this meant participation in political life. A person's *bios* is determined by their position in society. On the other hand, *zoē* is bare life, animal life. It is the aspect of life that governs simply living, such as eating and sleeping. Instrumental to Foucault's thesis on confinement and social segregation is his view on biological life as under the umbrella of politics. For Foucault, modernity is the shift to biopolitics: "at the threshold of the modern era, natural life begins to be included in the mechanisms and calculations of State power, and politics turns into biopolitics" (Foucault 1990 via Agamben 1998: 10). This was the "entry of *zoē* into the sphere of *polis* [political life]" (Agamben 1998, 10).

While Agamben agrees with Foucault that modernity, the end of sovereignty, is the state having control over both *zoē* and *bios*, he argues that Foucault fell short. Agamben writes:

> The Foucauldian thesis will then have to be corrected or, at least, completed, in the sense that what characterizes modern politics is not so much the inclusion of *zoē* in the *polis*… nor simply that fact that life as such becomes a principal object of the projections and calculations of State power. Instead the decisive fact is that, together with the process by which the exception everywhere becomes the rule, the realm of bare life… gradually begins to coincide with the political realm, and exclusion and inclusion, outside and inside, *bios* and *zoē*, right and fact, enter into

> a zone or irreducible indistinction. At once excluding bare life from and capturing it within the political order, the state of exception actually constituted, in its very separateness, the hidden foundation on which the entire political system rested (Agamben 1988, 12).

Agamben points to the irony of the modern state in which citizenship is based on bios and zoē. Science is leveraged to legitimize the marginalization of biologically inferior people, as in the case of eugenics, which legitimizes the stripping of *bios* from people determined genetically inferior. The system of measurement that is enfolded in the scientific regime of biology also legitimizes a dichotomy between normality and abnormality. People with disabilities fit snuggly within the category of the abnormal, as their bodies are scientifically proven to be pathological.

The modern state is distinguished by its power over the biological life (*zoē*) and assumes "the care of the nation's biological life as one of its proper tasks" (Agamben 1988: 99). The state can strip those who are deemed biologically unfit (this can be people of particular religions, ethnicities, nationalities, or abilities, for instance) of the rights that the state is meant to protect. Concentration camps exemplify a "state of exception," in which law (as the protection of rights) is suspended. Ironically, the state of *exception* is a rather *stable* political order in the nation-state. Within the state of exception, rather than citizens having control over their own lives, the lives of the inhabitants of these spaces are under control of the governmental regime. I agree with Agamben that that the institutions of confinement that Foucault identifies are states of exception, in that the inhabitants are legitimately stripped of what it means to be a human citizen. In both Agamben's state of exception and the marginal spaces in which people with disabilities often find themselves, people exist in a liminal zone. Their humanity is reduced. They are kept alive (or not, as in some concentration camps), but they do not often *thrive*.

The zone of exception applied to disability relates to disability historian Douglas Baynton's (2013) perspective that disability has been used to justify inequality throughout American history. Discourses about slavery noted that, as Black people were so mentally and physically weak, they were more likely to become disabled if granted freedom. Similarly, women gained the right to vote by proving that they were not feebleminded (mentally incompetent), as had been suggested by those opposed to women's suffrage. Immigrants were denied entry to the country on the assumption that some ethnicities were marred by mental and physical deficiency. These historical perspectives place disability as a factor that excludes one from citizenship. In Agamben's words, disability justified the stripping of *bios.*

Rehabilitation might be viewed an institution that returns the rights of citizenship to disabled people who have lost part of their humanity with the loss of function in their bodyminds. Concurrently, it is characterized by a history of confinement, established to segregate the abnormal population from the "normals" (Goffman 1963), or from the masses of citizens, practicing their own self-discipline (Foucault 1977). It is a liminal site that Snyder and Mitchell refer to as a cultural location of "violence, restriction, confinement, and absence of liberty for people with disabilities" (Synder and Mitchell 2006, x). This segregation is a consequence of modernity (Foucault 1977; 1988; 1990; Agamben 1988) and the eugenic and statistical means of understanding normality that fueled Enlightenment ways of knowing (Clare 2017; Davis 2013; Hacking 2000; Synder and Mitchell 2006).

Despite the ideologies of confinement that have influenced rehabilitation, including that practiced at Rancho, there is nonetheless a sense of community that exists among the disabled people who inhabit the space. Although this dissertation might be viewed as an attempt to "theorize the degree to which a dominant discourse such as rehabilitation science comes to be internalized by disabled people," (Synder and Mitchell 2006, 7), my research at Rancho reveals a surprising subversion of paternalistic attitudes towards disability that exist within the community. The spaces of marginalization that I describe do not merely pave the way to produce 'docile bodies' (Foucault 1977); they also become catalysts for new forms of subjectivity. In joining together in institutions, people generate a community and ultimately a disability identity. People appropriate the discourse of the institution with their own spin. In the next section, I examine one contemporary facet of the hospital - the (sometimes) paid disabled peer mentors who contribute to the sense of community among disabled people. I relate the practice of peer mentoring to the historical spaces of exclusion and confinement.

Peer mentors as contemporary poor farmers

Within the Agambenian framework of the state of exception, one can posit that the enterprise of rehabilitation presupposes disability's liminality. Rather than idealistically returning people with disabilities to normality, rehabilitation institutions may concurrently seek to maintain disabilities' exceptionality. At Rancho Los Amigos, this disposition is one possible justification of paternalistic labor practices in relation to people with disabilities. Since 2009, there has been a workforce of peer mentors at the hospital under the KnowBarriers program. Peer mentors are disabled people who mentor patients with similar conditions about any facet of life in which the patients might be interested. Essentially, they are paid or volunteer to be living embodiments of positive life with a disability for newly injured folks who do not know what to expect. I will explore in greater depth the ins and outs of their labor throughout the dissertation, but, in this chapter, I analyze peer mentoring as an exploitative form of labor like the poor farming that happened on the same campus a century earlier.

The disabled people who inhabit and later work at Rancho for low (sometimes unpaid) wages and hours as peer mentors do not simply blindly labor in this state of exception. How do they come to not simply accept their position as outsider but revel in it? It is possible that the people with disabilities who go on to accept positions as peer mentors have appropriated their marginal status and come to view it paradoxically as non-normatively ‘normal’. This disposition may constitute a form of hegemony (Gramsci 1971) or *symbolic violence* (Bourdieu 2004: 341), wherein the oppressed view the framework of their oppression as natural and “social law converted in an embodied law. Peer mentors do not question their low wages and limited opportunities to take control of an institution that is built to serve people like themselves with disabilities. Rather, they believe that their meager positions within the institution are justified. What’s more, they view their peer mentor positions as an opportunity to be morally just individuals. For instance, some of the peer mentors reflect on the positive opportunities that have been opened for them by their work at the hospital:

> “Mentoring to me has been a wonderful learning experience. It has helped me reflect on my own struggles and given me a sense of purpose and direction.”
>
> “I’m honored to help people because of the help that Rancho gave me.”
>
> “KnowBarriers [peer mentoring] gives me an opportunity to help others while helping myself. It makes me want to strive to be the best I can and helps me put my life in the right direction”

These quotes from the website of KnowBarriers peer mentoring program at Ranch Los Amigos are surprising, because they stress the good that Rancho has done for the peer mentors.

The KnowBarriers system is partially structured on the ‘giving back’ that peer mentors feel ethically obligated to perform. This is an understandable disposition, because those with disabilities often turn to other people with disabilities when they have questions or issues. With peer mentors, Rancho can capitalize on this sentiment of care. In offering people who want to ‘give back’ to the institution a low paid (sometimes unpaid) position, Rancho can frame itself as a progressive institution that employs disabled people and uses the increasingly popular peer mentor model.

This sentiment of “giving back” to the medical industrial complex that has confined disabled bodies for years is a haunting of the poor farm model. Pictures of the poor farm line the halls of the administration building. The institutional memory of the poor farm is codified in Fliedner’s positive historical account. Administrators proudly tout the long record of “care” for the most vulnerable members of society. During the first moments of training, peer mentor trainees are introduced to the L.A. County Poor Farm, whose interest in helping disabled people paved the way for the jobs they will hold. Rancho’s mission of confinement lives through its morally touted but marginally employed peer mentorship program. However, the peer mentors embody and socialize each other into a subversive community that is explored further in the remainder of this dissertation. While there are no archival accounts of tightly-knit bands of disabled inmates or patients, I suggest that the modern disability community is historically grounded in the natural rebellion and kinship that emerge among marginalized folks.

Conclusion

I have argued that Rancho Los Amigos’ history as a poor farm and the history of rehabilitation in general should be traced to institutions of confinement (Foucault 1988). The medical care for disabled people at Rancho is firmly rooted within the paradigm of biopolitics.

More than that, however, it is also rooted within regimes of abandonment (Biehl 2005), exceptionality (Agamben 1998), exclusion (Baynton 2013), and symbolic violence (Bourdieu 2004). This history is one fiber that weaves in and out of the institution today. Yet, it does not comprise the entire canvas. In the remainder of this dissertation, I examine how, despite this historical force of exclusion, spaces for subjectivity and sociality open, like rips in the canvas.

In the modern-day hospital, north of Imperial Highway, the campus smelled constantly of industry during my fieldwork. The hospital was undergoing construction of its newest addition, the completely wheelchair accessible Wellness Center and the new outpatient center, where the many disabled peers will no doubt congregate in the years to come. While the fire was raging south of the highway in the abandoned building of the poor farm on February 1, 2017, construction workers were busy raising the metal support for the modern looking shade that would cover the courtyard outside of the new wellness center (see Figure 2.5).

Figure 2.5: Architectural plan for Rancho's future: the new wellness center and the adjoining outpatient center to be completed by 2020. The image pictures a sunny morning in Downey. A blue-sky lays on top of new white buildings with an architecturally interesting shade and spire that draw the eye in. On white concrete, people walking and pushing wheelchairs go about their days. Image credit: Taylor Design.

In the geographical make-up of Rancho, the old-fashioned approach to care is abandoned, left to rot south of the highway. The buildings have been surveyed for historical significance. However, the disrepair of "Old Rancho," as it is referred to by Rancho staff and community members, prevented this classification (HABS CA-2800). While many people who frequent the modern institution talk about Old Rancho, they do not toil there. The fact that Rancho has a long history is a cherished piece of information for people, but the physical space holds little affective significance. Yet, just as generativity springs from the margins among disabled people at Rancho, Old Rancho hosts small, unexpected moments of joy and community. The buildings are now colonized by feral cats, fed by nearby residents, despite the frequent signs that demand: "DON'T FEED THE CATS."

As the old buildings of the poor farm decay and burn, new buildings and modern approaches to rehabilitation arise. Yet, the history of the poor farm cannot be merely be abandoned, as it infuses the institutional climate today. Rancho Los Amigos, including the approach to rehabilitation it has fostered, is a combination of a space of exclusion and a ground for the emergence of new subjectivities. An historical focus is crucial to adequately describe the generative force of disability that fuels Rancho into the future.

As a poor farm and as a rehabilitation hospital, Rancho has been and remains a gathering place for people who are marginalized. Many of the discharged inpatients return weekly, sometimes daily, to the hospital. They return not just for outpatient medical care but also for the sense of inclusion that only exists there, where disability is commonplace. In the remainder of this dissertation, I argue that remnants of the poor farm model still characterize the hospital today. For instance, the inclusion for the excluded members of society is one artifact of Rancho's past as a poor farm, a remnant of the past that this paper seeks to excavate. While the hospital no longer provides long-term housing to the destitute citizens of Southern California, it does have an uncanny draw for people with disabilities who find themselves returning to it. While Rancho has grown into a modern medical facility that leads in research on stroke, traumatic brain injury and spinal cord injury, a vestige of the poor farm work model lingers in some of the current hiring practices and programs related to disabled patients. Across Imperial Highway from the modern facility, sits the relics of the old poor farm. The grass is overgrown. The windows are boarded up. Buildings that used to house L.A. County Poor Farm's inmates are decaying and covered in graffiti. The poorhouse model haunts the modern hospital in substance and in paradigm. Fire cannot destroy the history that has built this space of both marginalization and, as I will discuss in the next chapters, generative community.

Figure 2.6: Old Rancho boarded-up infirmary. In the foreground, the image shows a "No trespassing sign" hanging on a barbed wire fence. In the background, behind the fence, an old, decaying building with the windows boarded up sits among dead, overgrown weeds. Photo by author.

Figure 2.7: Sunrise at Old Rancho. The image shows a street running between former hospital buildings made of brick and concrete. The paint on the buildings is chipped and the windows are covered with boards. Dried weeds spring from the cracks in the street. Photo by author.

Figure 2.8: Fenced in Old Rancho administration building. In the image, A chain-link fence obscures the view of a building, with the year of its construction, 1926, mounted on a grand entryway. The building is white with deep red rooftiles, built in the Spanish Colonial Revival style. Well-manicured pants adorn the front entrance. Photo by author.

Figure 2.9: Flowers sprouting from the ruin of Old Rancho. In the photo, a white dandelion flower sprouts stretches out through the holes of a chain-link fence. Photo by author.

Figure 2.10: Poor farm water tank and smokestack. The image shows an old Art Deco building with windows painted white and paint chipping with a smokestack emanating from the middle. Next to the building is a water tower, stretching even higher than the smokestack. The turquoise paint on the water tower is obviously faded from years exposure to the sun. It also appears to be partially covered in graffiti. Photo by author.

Figure 2.11: Walkway in the present-day hospital. The image shows a covered, brick walkway with pillars adorning each side of the walkway. The sidewalk, once painted a deep red, has faded through use. Photo by author.

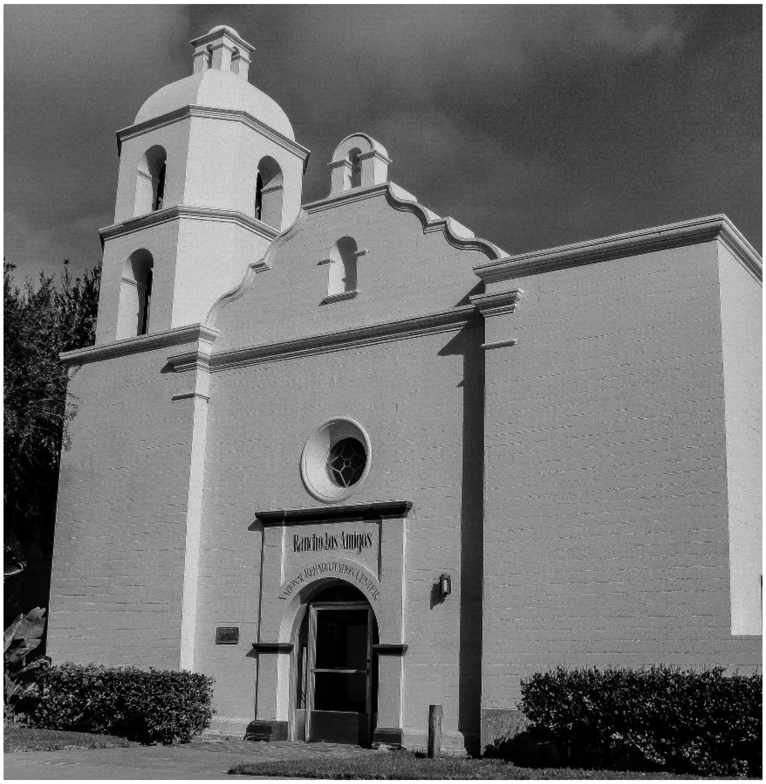

Figure 2.12: Administration building on present-day Rancho campus. The photo is a black and white image of a Spanish Colonial Revival building with the words "Rancho Los Amigos National Rehabilitation Center" painted over the main entrance. Photo by author.

Figure 2.13: "Rancho Rising" construction. The color photograph shows a fence, blocking pedestrians from construction in the background. The fence has a banner reading "Rancho Rising 2020: Building on Our History of Hope and Healing," which is partially falling off. In the background, a construction worker sits on an elevated crane next to a freshly constructed white tower, the focal point of the new construction on the hospital. Photo by author.

CHAPTER THREE: Thick Sociality

Intro: Disability habitus

My first time visiting Rancho Los Amigos Rehabilitation Hospital, I had heard of it several times from other disabled folks in the Los Angeles area. Interestingly, it was a physical therapist, whom I was seeing for treatment for phantom limb pain who helped me get myself established at the hospital. According to Merleau-Ponty (2005), the phantom limb, which is the feeling that an amputee still has the missing limb, is evidence of the combination of psychological (memories of living with the limb) and physiological (neural pathways from the brain to the limb) factors that come together in his embodied theory of phenomenology. It must have been kismet that my physical therapist who worked with me on such a phenomenological topic would help establish my connection to my field site, where I would conduct research for my dissertation on the phenomenology of disability. Her partner was a physical therapist at Rancho. She also had a good friend who was a woman with a spinal cord injury who worked as a social worker there. Through her connections, my spouse, Courtney, ended up getting an employment opportunity with the hospital, something which came as a welcome relief to her, as she had been struggling finding a job since we had moved to Los Angeles. Opportunities were especially tricky for her because of job discrimination with a disability.[1]

On the first visit, Courtney and I were stopping at the hospital to pick up something that she had left at work. My first impression was that it was a rundown institution; the buildings were old and looked like they were only a few years from falling apart; the decor felt from the

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[1] Courtney had searched for months to find a job to no avail. She could not even get employment for low-skilled work. For instance, upon entering a store to apply for a receptionist position, the employees in the store wanted to know exactly how she would be able to perform her job functions from a wheelchair. Once she was finally hired in a full-time position, she learned that the able-bodied person who performed essentially the same job that she did was given a salary nearly twice hers.

1980's or earlier; the walls yellowing. The disabled people who inhabited the space were different from those I encountered at wheelchair basketball tournaments. At the tournaments, I saw mostly white young adults from middle-class backgrounds using nice, sporty looking chairs (purchased, undoubtedly by private insurance or through personal funds). The athletes were people with lower limb disabilities that inhibited mobility but were not so disabling that a person could not move themselves on their own. This group was a largely mobile group of disabled people who fully embraced middle-class American neoliberal values of independence (e.g. Zola 1982) and the go-getter attitude as ideal citizens in the able-nationalist framework (Snyder and Mitchell 2010) and hegemony of productivity (e.g. Mitchell and Snyder 2010; Rupert 1990; Weber 2002 [1905]; Weeks 2011). When I began to meet the folks who made up the fabric of Rancho's sociality, I realized my subconsciously operating notions of what everyday disability looked, sounded and smelled like - my phenomenological orientation to disability - would need to expand. I follow Ochs and Solomon in understanding sociality as an interactionally established phenomenon, specifically, "a range of possibilities for social coordination with others that is influenced by the dynamics of both individuals and social groups" (2010, 69).

When Courtney and I pulled into one of the many parking lots at Rancho, we saw a woman whom my wife knew from work. She was an African American, relatively new outpatient who looked to be about forty, with a soft belly wrapped in a tight pink t-shirt, a knit skirt, and feet enclosed in soft suede boots lined with synthetic fur. Black crimped hair cascaded down her shoulders. By looking at the way she sat and moved her wheelchair, I assumed that she had a spinal cord injury (a disability with which I was intimately familiar), although I found myself questioning why her body behaved as it did. Her wheelchair looked a bit wide for her hips. After spending many months around rehabilitating and rehabilitated disabled people, I learned that people often leave the hospital in chairs that are too big for them. Her legs splayed to the sides, seeming to have a mind of their own. Her skirt gently draped between her knees, from between which emerged a tube that linked to the catheter bag strapped to her chair behind her right foot. Her lower back gently curled forward, so I surmised that her injury was somewhere above her navel, which would likely result in weakened abdominal muscles, making it difficult to hold a straight posture. She acknowledged me with a smile and warmly greeted Courtney. While I tend to feel an affinity to disabled folks, the woman was not surprised by my presence. I did not seem to get the look of identification that I do in spaces where disability is unexpected. Instead, she interacted with Courtney, who seemed to have quickly made herself a figure in Rancho's community. Courtney asked her if she had gotten a cushion yet. She replied, "I'm working on that, I tried to make an appointment at the seating center." We left her, to roll inside, as she sat waiting outside in the sun.

I did not know why the woman was waiting outside. After months of fieldwork, I came to realize that waiting was a part of the sociality at Rancho. Many people relied on an affordable transit system for disabled people called Access, which would pick them up and drop them off anywhere in L.A. County. To book an Access ride, riders had to select a two-hour time frame within which they could be picked up. Consequently, many people would book their rides and spend hours on the campus waiting for their van to retrieve them. Additionally, they enjoyed staying on the campus to socialize with the employees, patients and community members whose daily routines circulated around the institution. Some had recreational classes or activities and medical appointments to attend. Others would spend days at a time working through the public institution's bureaucracy to get appointments. They would often kill the time waiting in the sun and chatting with passersby.

On the way inside the building, Courtney whispered to me about her acquaintance in the parking lot, “she sits without a cushion and it drives me crazy.” Immediately, I knew what Courtney was referring to and why the woman looked as if something was off in the way that she sat in her chair. Sitting on the pan of a wheelchair with no cushion is uncommon because the cushion provides posture support. More importantly, a cushion prevents injury to the skin. Sitting without a cushion makes one much more prone to pressure ulcers, skin breakdown that occurs from excessive pressure without movement, particularly in areas where circulation is limited, as it often is in the lower limbs of people with spinal cord injuries. Pressure ulcers if untreated can land people in the hospital for months, in need of a skin graft surgery. They can also, if they become infected, be fatal. Courtney referred to the woman’s preference for no cushion as “driving her crazy” because of the risk in which she was placing her body.

I also realized that the woman’s body had momentarily thrown me out of my *disability habitus*: the largely unconscious embodied way of moving with my own disability and interpreting the disabilities of others. Here I expand Bourdieu’s notion of habitus (1977; 1990a; 1990b), “an internalized structure or set of structures… that determines how an individual acts in and reacts to the world” (Throop and Murphy 2012), to refer to the way in which my experiences with disability have influenced orientation to the ‘disability world’ (Ginsburg and Rapp 2013). Ochs and Solomon specify that habitus is “a circumscribed yet transformable set of dispositions and situated logics that members of social groups employ to interpret and enact social practices” (2010, 72). By the often subconscious structures of my disability habitus, I move my disabled bodymind (push my wheelchair, hold my posture, transfer into and out of my chair, open and move through doors, etc.) in the ways that I have learned through interaction with other disabled folks. Furthermore, I have learned to automatically read the movements and adornments of folks with visible disabilities and figure them into a disability world, full of intersecting class, racial, ethnic, and ability distinctions (Crenshaw 1989; Ervelles and Minear 2010; Moodley and Graham 2015; Nash 2008).

In this case, the woman's lack of cushion, her wide chair and her catheter had, on a phenomenological level, surprised me. I did not realize in that moment that I was operating on disability knowledge (Hartblay 2019) that I had inherited from years of living with a disability and interacting in disability communities (largely a disability sports community at that point). I had not adjusted yet to the norms of this community, where people had different expectations for what disabled bodies would look like and how they would interact with the world, including assistive technology, like the cushion-less wheelchair on which this woman sat. The community members of Rancho also operated on a different timeline because of the dense bureaucracies of public insurance. Trying to get an appointment at the seating center (or acquiring other assistive technology) for those with limited resources and knowledge of insurance could entail weeks of talking to administrators, signing forms, arguing with federal organizations, and general exhaustion. This bureaucracy to which the state seems attached (Graeber 2015), perhaps, explained why the woman had not managed to get an appointment for her cushion. I had not yet adjusted to the halting pace of getting necessary equipment and care.

In this chapter, I unpack the structure of Rancho's community, which imbues a disability habitus. I outline some - often unspoken - community norms that structure the disability habitus at Rancho. I also argue for a multidimensional approach to community that combines some local norms and ideologies with institutional context and practices. While a great deal of scholarship has been produced on the notion of community, there has been a lack of dialogue across disciplines. Jansen argues that "no attempt has been made to… develop a genuinely interdisciplinary approach to community" (2020, 9). This presents a pragmatic dilemma for rehabilitation because, as I argue in this chapter, community can be an essential space for rehabilitation. Therefore, a lack of robust theoretical orientation to community is problematic for rehabilitation science, which seems to rely on an unexamined sense of community as an interconnected system of relationships that existed before a person's injury into which the rehabilitating person should become integrated again after injury. As I will demonstrate, this set of assumptions yields a limiting definition of community. A rich, deep sense of community can emerge among people in similar life situations (like those with lived experience with disability), who have been brought together through the institutional context of rehabilitation. Efforts to incorporate community of people with similar experiences into physical rehabilitation could fundamentally shift the medical practice, which has largely disregarded the value of the lived experience of disability.

This chapter attends to the disability community itself, which is an important aspect of rehabilitation. I introduce a theory of community grounded in rehabilitation science (community integration as a goal of rehab), anthropology (community as a social desire, despite increasing de-centralization), and sociolinguistics (adaptations of the speech community and communities of practice). I approach community as an object that is continually structured and re-structured through everyday interactions. Drawing on field notes and recorded conversations among peer mentors, outpatients and disabled community members, I argue that Rancho is a place of thick disability sociality in which people can begin to build a disability habitus and where social attachments among disabled folks can form. I believe this community is essential for the practice of rehabilitation, which has failed to acknowledge its potential benefit. Figure 3.1 outlines the theoretical foci of this chapter, including disability habitus, generated and transformed through daily encounters in the hospital, encircled by social relationships, enclosed in disability community.

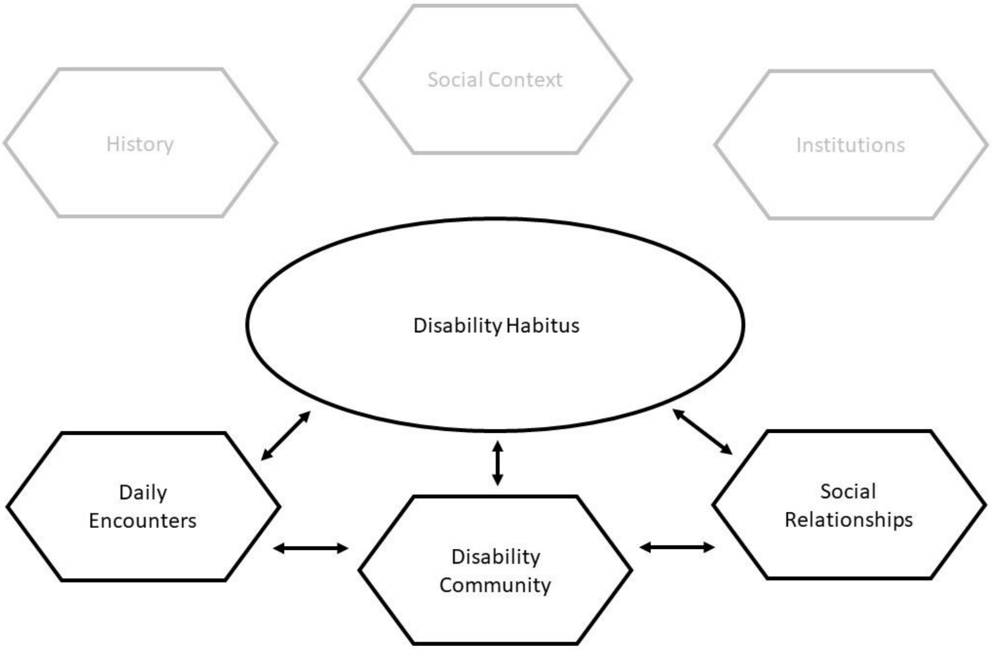

Figure 3.1: Contours of disability habitus and community. The image depicts the interacting facets of disability habitus with which this chapter deals: daily encounters, social relationships and disability community.

Thick sociality

During fieldwork when my workload was slow, I used to wander Rancho's halls and stare at the pictures that studded the walls. The walls of the administration building were filled with black and white photographs dating back to the poor farm of inmates caring for farm animals, posing in front of the buildings. The walls of the outpatient building were covered in color photographs from the 1980s and 1990s of patients (mostly those with SCIs) hooked up to machines, wires tracing connections from electrodes to machines meant to measure their nerves, or working with clinicians on some of the cutting edge technologies that had been developed at the hospital. On the second floor of the inpatient building, former patients' art lined the halls.

Near the cafe in the inpatient building, a glass frame housed trophies, awards and pictures for Rancho's wheelchair sports teams. It was not uncommon for consultants to point out photographs of themselves, freezing in time their identities from years ago, or describe their artwork that memorialized their contribution to the hospital. These physical markings were artifacts of the hospital's historically grounded disability sociality that has combined labor, work, art and other enjoyment activities with cutting edge medical technology, all of which contribute to the hospital's thick sociality.

Thick sociality, borrowing from Geertz's "thick description" (1973) describes the deep and multifaceted social relationships at Rancho, as well as the possibility for interaction (Ochs and Solomon 2010) that depend on the context of rehabilitation. Geertz's notion of thick description views ethnography as a method that allows the participant observer to contextualize details of daily events within larger social structures and symbolic meanings:

> The concept of culture I espouse… is essentially a semiotic one. I believe, with Max Weber, that man is an animal suspended in webs of significance he himself has spun, I take culture to be those webs, and the analysis of it to be therefore not an experimental science in search of law but an interpretive one in search of meaning (Geertz 1973, 5).

In this dissertation, thick sociality refers to a dense web of relationships (or, a la Ochs and Solomon, the *possibility* for social coordination) that are part of the palpable milieu at Rancho. Thick sociality is also a response to Wool's notion of "thin sociality." In her research on Fisher House, a communal house for injured soldiers released from rehabilitation at Walter Reed, Wool depicts a tangible sense of sociality that permeates the halls. She describes a thin sense of sociality that emerges among the injured soldiers, for whom "layers of the social skin" that were "sloughed away but never left to rest, callusing and blistering in the intensity and friction of new modes of life and sociality" (Wool 2015: Kindle location 776 of 6054). Thin sociality describes the obstructed, distanced relationships among the wounded at Walter Reed. It is thin because the injured soldiers are too torn apart in their bodyminds from the violence and trauma war to form intimate bonds with each other.

The social context at Rancho is different, in that if offers rehabilitation to people as both inpatients and outpatients. While I did not see many inpatients return to become integrated into the community within the months of fieldwork, I met many community members, often former patients who returned to the campus after years away. Açıksöz (2020a) beautifully depicts community among disabled veterans in Turkey in which shared loss, trauma, and experiences of stigma generate intersubjective spaces in which healing is possible. Conversely, Rancho's communal sensitivity is imbued with positivity. Disabled folks who encounter each other typically do not discuss the trauma and loss that is ever present, filling the silence. Discussions of loss are typically only encouraged in conversation with newly injured patients. Even in support groups, disclosures of difficulty are often met with descriptions from other disabled folks of their gratitude. There is a mood of positivity and hope with which discussions of disability are often steeped. This mood is also present in the institution. The Rancho's halls are covered in pictures of smiling patients, poor farm inmates, doctors, and administrators toiling in their seemingly happy work. Patients and community members are encouraged to share their creative projects in art and dance classes and nearly monthly art shows or performances. There is a strong sense of close community and familiarity among disabled people that contributes to this thick sociality (see Figures 3.2, 3.3, and 3.4). Thus, I argue that, in contrast to the keep-to-oneself demeanor described by Wool, there is a thick sense of sociality at Rancho, where people can return after they have had the space and time to make a home in their new bodies.

Ochs and Solomon (2010) outline autistic sociality, which they describe as a range of possibilities for social interaction influenced by social context, competencies and impairment. Similarly, I see the sociality that exists at Rancho as influenced by the social and historical context of the institution, the cultural orientations of the community members, and the disabilities and rehabilitation that bring them together. This predilection is obvious among the peer mentors, whose primary job is to engender hope for newly disabled folks. A person's ability to weave hope into their lives after an injury is variable and depends partially on the social structure into which he or she is embedded (Mattingly 1998; 2010). This thick sociality is the ever-present possibility for social relationships and belonging among people with non-normative (disabled) bodyminds, and it is the basis for disability community at the institution. It is especially alluring to disabled poor people who can find affordable or free medical care as well as recreational opportunities, like art classes or a membership at the Wellness Center (see figure 3.5). This sociality allows disabled people to develop an orientation to disability; it is an influencing force in disability habitus formation. The sociality is imbued with a positivity that transforms into "intersubjective healing" (Açıksöz 2020a), however the loss and trauma of disability inhabits the silence of avoided discussions.

Figure 3.2: Artist stands by paintings at Rancho art show. A man standing supported with a four-pronged cane is next to a display of his paintings, including a whimsical surfer and an image that looks like a beach scene. Photo by author.

Figure 3.3: Seated artist displays his paintings. The image shows a man sitting in a chair between panels of hanging artwork. Photo by author.

Figure 3.4: Boy completes obstacle course at Rancho SCI Games. In the image, a young boy using a wheelchair goes down a step surrounded by three women. Photo by author.

Group Classes Schedule

Monday	Tuesday	Wednesday	Thursday	Friday
10:00 am English Class	10:00 am Restorative Gardening* 900 building	8:00 am Adaptive Cycling Exercise Group* Entrance of Don Knabe Wellness Center ***To participate call (562) 385-6600***	10:00 am Restorative Gardening* * 900 building	
12:00 pm Walk/Roll/Run* Marilyn Hilton Garden	10:00 am Brains in Motion	10:45am Stroke support Group	10:00 am MS support group* * 900 building, unit 901, room 10	
12:00 pm Brain Injury Support Group	11:00 am Seated Tai Chi (last Tuesday of every month)	11:00 am All Things Web (1st Wednesday of every month)	10:00am Life Beyond Aphasia (English)	
12:00 pm SCI Support Group (English)	12:15 pm Mat Pilates	12:10 pm Zumba Fitness	11:00 am Life Beyond Aphasia (Spanish)	
12:15 pm Zumba Fitness	1:00 pm Artists on the Rise	12:10 pm Wellness for the Soul	11:00 am Intro to Wheelchair Sports* 900 Building, Basketball Courts	10:00 am English Class
1:00 pm Driver's Training Support Group* Contact Wellness Center for specific dates * 900 building, room 88A	1:00 pm In Home Supportive Services (IHSS) (1st and 3rd Tuesday of every month)	1:00pm Exploring the Performing Arts (4th Wednesday of every month)	12:15 pm Kundalini Yoga	11:00 am Caregiver Support Group *900 building unit 901, room 8
1:00 pm Artists on the Rise	1:15 pm Zumba Gold	1:00pm Stroke support Group	12:00 pm SCI Support Group (Spanish)	12:10 pm Zumba Fitness
2:00pm Diabetes Support Group* 900 building, 904/5 Solarium		1:30pm Bingo (1st and 3rd Wednesday of every month)	1:15 pm Zumba Gold	1:00 pm So You Think You Can't Dance? *no class on 1/6; 2/10; 3/24*
5:30 pm Zumba Fitness		2:00 pm KnowBarriers Life Coaching Program (4th Wednesday of every month)	2:00pm Brains in motion	
		5:30pm Zumba Fitness	1:00pm Aromatherapy (3rd Thursday of every month)	
			2:00pm Meditation	

Wellness classes provide support for patients, caregivers, and community members of different abilities. Small group sizes provide education and support to help cope with challenges brought about by new life changes.

The Don Knabe Wellness Center offers a variety of classes designed to improve balance, strength, endurance, and coordination regardless of physical ability.

Wellness classes promote relaxation, meditation, and creative exploration. They focus on teaching strategies to achieve and sustain a healthy lifestyle.

7601 E. Imperial Hwy, Downey, CA 90242 (562) 385-7111 TTY/TDD: (562) 385-8450
CLASSES WILL BE HELD BASED ON INSTRUCTOR AVAILABILITY.
SOME CLASSES MAY CANCEL DAY OF SESSION, WITHOUT PRIOR NOTIFICATION.

(562) 385-6600 RLAWellness@dhs.lacounty.gov

Figure 3.5: Rancho’s weekly class schedule offered *at the Don Knabe Wellness Center. The schedule includes classes that are available to anyone with an affordable monthly membership, including disabled folks.*

The sociality at Rancho promotes a strong community of disabled people, or, in Goffman's words (1963), fellow "sufferers," to flourish. Its many programs, such as art, exercise, dance, yoga and gardening classes demonstrated on the schedule in Figure 3.5, provide social engagements for disabled people. Sociality is also lodged in the daily interpersonal relationships that Rancho community members form with each other. In the next section, I examine Rancho's disability habitus undergirding its thick sociality.

Orienting to Rancho's disability habitus

The disability habitus entails developing an intuitive knowledge of different environments. The folks at Rancho differ in many ways from disability communities in which I had previously been embedded. First, the members are more diverse. The SCI population with whom I interacted during fieldwork is depicted by the institution as an underserved population, "including individuals from racial and ethnic minorities (80% of [the] SCI population) and those from economically-disadvantaged backgrounds (over 50% of [the] SCI population)" (Rancho Los Amigos Rehabilitation Center, n.d). Rancho is a public institution and a safety-net hospital, which means they treat anyone, regardless of their insurance status. As such, they see many patients on state and federal insurance programs (Medi-Cal, for people with disabilities and/ or limited income, and Medicare, for retired people and/ or those who receive disability work benefits) and those without insurance. This economic status was visible in some of the wheelchairs that Rancho folks rode. Medi-Cal and Medicare will not purchase top of the line wheelchairs or equipment, like the highly coveted Spinergy wheels with carbon fiber threads in the spokes. Therefore, the manual chairs that low-income disabled people use often do not resemble the sleek, ultra-light titanium chairs preferred by many of the athletes whom I had previously known (Bloom 2019). Those without insurance are left to their own devices to find chairs, which usually involves buying them through peer networks, getting hand-me-downs from friends, and using their own wheelchairs for many years beyond the typical life span of a chair. Many of the wheelchairs that I saw were older, with paint scratched off and obvious rigging and handmade fixes. Despite this state of affairs, wheelchair-users often found ways to imbue their chairs and mobility technologies with personality. For instance, an interlocutor and friend, DB, rode through the campus on a power wheelchair that he had adjusted by removing the speed governing system imposed by the medical supplies technology. This allowed him to fly through the campus at about 8 miles per hour. In addition, he had installed a blue speaker in his headrest so that his journeys could be improved by the 1970's era funk and disco that he preferred.

Additionally, the disabilities of Rancho community members ranged much more broadly than the disabilities that I had grown accustomed to among my athlete friends (typically lower mobility disabilities with which the disabled person could get around independently). Rancho primarily serves people with SCIs, stroke, and TBIs. Some people used power wheelchairs, which they moved with their mouths, as the muscles from their neck down were paralyzed; some pushed manual wheelchairs without help; some were pushed in wheelchairs; some walked with an uneven gait and crutches, canes or walkers; some walked with no visible disability; and some still moved themselves in other ways. Unlike wheelchair basketball players, who tend to mock the use of power wheelchairs or non-independent mobility, the disabled people at Rancho did not seem to show an overwhelming preference for one way of getting around over another.

When disabled people at the hospital looked at me, I felt as though they were looking at someone they knew. And soon enough, they did. It did not take many visits to learn the names of faces of the regulars at the hospital. While my attention was at first drawn to the alternate sense of reality that such a space of marginalization entails, it did not take long to realize that there was also a vibrant community. Indeed, its sense of exclusion and abjection (Butler 2011; Kristeva 1982) made the queer collection of community members so enticing. For instance, during interactions with peer mentors and inpatients, my advice on life with a disability was frequently solicited. While I was not an official peer mentor, my lived experience positioned me as someone with disability knowledge. I was encouraged by other disabled folks to participate in the knowledge-sharing exchanges that contributed to the sense of crip communion. I often found myself so mysteriously pulled into these conversations that I forgot my role as the silent, note-taking anthropologist and eagerly shared the tricks, mistakes and stories I had collected since entering the ranks of "the disabled."

Through fieldwork, it became evident that research participants, among others, thought of Rancho as its own microcosm of community. This community lived in the people there and in the hospital's built environment. On a characteristically warm, dry day in Downey, I interviewed Juice, an SCI peer mentor. After discussing his disability, his rehabilitation, and his work, he thought it would be a good idea to show me around the halls. He told me that spending time at Rancho was a way for him to stay away from his 'old life' (as an able-bodied but physically and morally unhealthy person). Rancho was also a place where he felt completely at home - where he saw other people with disabilities, former doctors, therapists, and friends. These people knew him in the most vulnerable part of his life; they were an integral part of his new life. And he became a part of the place itself. He explained, "If you look around Rancho, in the walls, you'll see me." We rolled through the hallways in the building where he was working that day and, as if showing off family photos, he pointed out the pictures of himself from his years of participation in Rancho's programs, like sports, and performing arts, as well as his volunteer work. Yet, Juice's desire to have himself commemorated in pictures on the walls was not enough:

> I feel comfortable here… to the point where I spoke with the CEO and I asked him that, before my time on this earth h@@ ends, I want a statue of me here… Not a big old name tag on the tree of life, I want a bust! (I want SOMETHING) of me here!

Juice's longing to leave a visible impact on the physical setting of Rancho implied that Rancho had provided an integral sense of community to him; and he, in return, had impacted that community. Like me, Juice saw the thick sociality at Rancho. As an active contributor to the community, he wanted to leave his literal mark on the hospital.

What is community in rehabilitation science?

The officially inscribed primary goal of rehabilitation is to "assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments" (World Health Organization 2011, 96). Depending on the clinician, a major part of "optimal functioning" is community integration. McColl et al. (2001, 429) argue that "community integration is arguably the ultimate aim of rehabilitation. Presumably, every person participating in rehabilitation hopes to be happily situated, productively occupied, and effectively supported in the community". According to this vision of rehabilitation, community integration is the "opposite of handicap, where handicap has been defined as the social disadvantage resulting from disability or impairment" (Ibid. 2001, 429). The approach to community integration is well established in research on rehabilitation. The federal government's arm of disability research, the National Institute on Disability, Independent Living and Rehabilitation Research recently announced $1,000,000 in grants to fund research on disability and community integration and participation (Administration for Community Living 2019). Furthermore, quantitative instruments designed by rehabilitation scientists measure varying levels of community integration, including the Community Integration Questionnaire (Willer et al. 1993), the Reintegration to Normal Living Index (Wood et al. 1988), the Craig Handicap Assessment and Reporting Tool (Whiteneck et al. 1992), and the Community Integration Measure (McColl et al. 2001). Each community integration measure is designed to assess a person's ability to function based on factors in their environment. These community integration metrics are typically used to measure a person's degree of rehabilitation and have been used in a number of studies to evaluate the rates of specific populations' rehabilitation (e.g. Rath et al. 2003; Shigekane 2007; Willer et al. 1993) and the efficacy of certain rehabilitative treatments (e.g. Cicerone et al. 2004; Goranson et al. 2003; Hanson et al. 2001; Kim and Colantonio 2010).

In this paradigm, community integration comprises factors such as assimilation, relationships, occupation and living situation (see Figure 3.6). Yet, as Figure 3.6 demonstrates, this theory is unreflective of the social ideologies that configure this sense of community. For instance, some of the factors that contribute to community integration in the graphic, like independence, productivity, and conformity, are steeped in neoliberal ideologies. The graphic in Figure 3.6, a common approach to community integration in this discipline, seems to have been taken straight from Foucault's (1977) genealogy of biomedicine, in that the goal of this approach to rehabilitation is measure the 'docility' of the bodymind under study. In assuming that the goal of rehabilitation is a conforming (docile) person that is productive (creating capital) and independent (self-surveilling), this rendering of rehabilitation reproduces social ideologies about production and independence, rather than attunement to ideologies that inform the communities at hand.

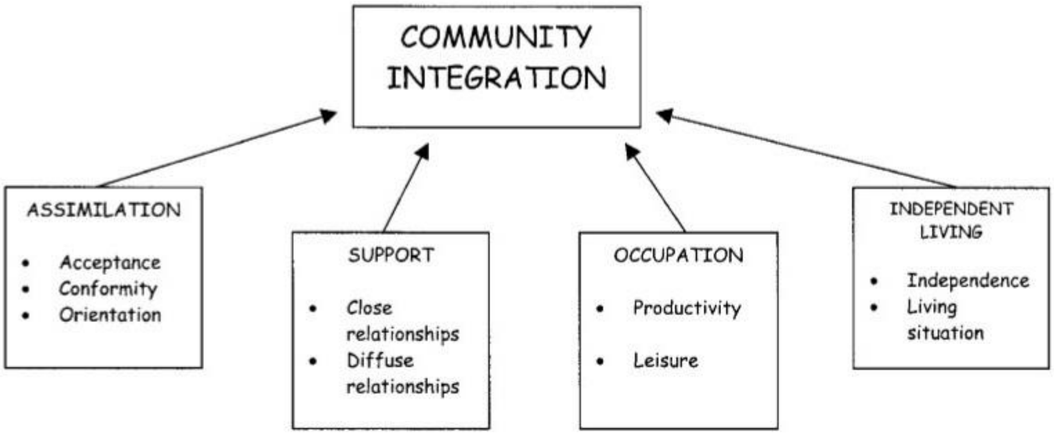

Figure 3.6: Depiction of community integration from McColl et al.'s study (1998). Assimilation, support, occupation, and independent living are all contributing factors for this definition of community integration. Image from screen shot of McColl et al. 2001, 430.

Despite its indifference to socio-political ideologies, this approach to rehabilitation is distinct from other approaches. Studies of community integration in rehabilitation are multidimensional and emphasize the context of the rehabilitating individual, despite the field's tendency to valorize individualism. The emphasis on community resonates with the ethnographic sensibilities I accrued during fieldwork. From the moment that I arrived at Rancho I felt some tangible sense of community (an orientation that I feel often among other disabled folks). Despite the reproduction of neoliberal values, the Community Integration Measure (CIM) developed by McColl et al. (2001) appealed to me, because it did not heavily weight the importance of a person's independence (see Appendix 3 for the complete CIM). In this measure, a person can be integrated into a community, regardless of whether or not they accomplish tasks independently.

Community is a critical perspective that most rehabilitation science misses, because it un-weights the individual and takes into account the social context of the rehabilitating person's success. One problem with this measure is that the imagination of community is quite limiting. An underlying assumption of its design is that a person belongs only to one community. As I will discuss in the following sections, there are many communities in which a person can participate and feel a sense of belonging. One of these communities, as discussed in the previous section, is the community of rehabilitation among disabled folks at Rancho itself. In addition to feeling a visceral sense of sociality that permeates the institution, many considered Rancho an important community. For instance, during an outpatient SCI physical therapy session that I observed, one patient told me, "I'm all about anything Rancho. It's totally different being with your wheelchair family." His statement makes the connection between Rancho, disability and community clear, going so far as to expand traditional notions of kinship to envelope the sense of familiarity he feels among peers with whom he identifies (Kafer 2019; Rapp and Gisnburg 2001; 2011).

While there is an undeniable sense of family that the members of Rancho feel, some of their comments tend to downplay the presence of the institution. For instance, one peer mentor, Forest, explained his view of Rancho as a comforting, in-between environment where disabled folks could prepare to enter "the community":

> It's like a family atmosphere. Yeah, we all we all kind of get each other. And for a lot of people, that's their safe haven. They can go somewhere where they're not gonna be judged. I would say that's huge for Rancho, too, because it's that first steppingstone getting out of your - home setting into the community. But yet you can see people who are in wheelchairs. Um, you're at a safe - you know, you're at a safe place.

According to Forest's logic, Rancho is an intermediary space between home and the community. Thus, for Forest, it is not a community.

Similarly, Ed explained his attachment to Rancho this way:

> I've been joined at the hip with Rancho since my initial injury… You have a catastrophic injury and one of the steps in rehabilitation is getting back out into community. But I noticed I never completely get back into the community because I'm still here. I would come from school or come from an activity and I would de-stress here… You're out there in the real world and dealing with issues. People deal with you differently when you're a wheelchair user. But I'd come back and I would stop and de-stress here on the way home…

Ed's explanation draws a distinction between Rancho and the "community," as he sees himself not returning to "community," because Rancho was the place that he found himself returning to in moments of vulnerability, those when he needed to "de-stress." He also contrasts Rancho and the "real world," where disabled people are treated differently.

It is interesting that participants, as well as rehabilitation scholars, are resistant to recognizing Rancho (or rehab facilities generally) as a legitimate "community" I suggest this invisibility is due to the abiding stigma associated with disability, according to which a gathering of "fellow sufferers" is a "half-world," (Goffman 1963, 21). Additionally, scholars who have conducted research with groups of disabled people in medical settings emphasize the synthetic nature of social connections; people come together (sometimes against their will) because of a shared bodymind identity that they may not wish to adopt (Evans et al. 2020; Wool 2015). While such ideologies could diminish the cohesiveness of community at Rancho, the history of the poor farm and the thick sociality of the place suggest otherwise. Despite participants' tendency to not to recognize Rancho as an official community, their responses to a survey that I administered suggest, instead, that they commit to Rancho as a deep community into which they are well integrated.

During fieldwork, I adapted the CIM and administered it to the research participants whom I interviewed. I asked participants to imagine Rancho each time I used the word community. I removed several questions that did not make sense, given the new format I introduced (see Appendix 4 for the adapted CIM). I asked participants to indicate their level of agreement with the following statements, and encouraged them to expand on their answers when it felt appropriate:

1. I feel like part of this community, like I belong here.
2. I know my way around this community.
3. I feel that I am accepted in this community.
4. I can be independent in this community.
5. There are people I feel close to in this community.
6. I know a number of people in this community well enough to say hello and have them say hello back.
7. There are things that I can do in this community for fun in my free time.

Having participants consider Rancho as the community in question led nearly all the people in the study to indicate that they were highly integrated into it. For each of the seven statements, at least 75% (15 out of 20) of respondents strongly agreed. Only one respondent indicated disagreement with one question (one person indicated “somewhat disagree” to statement 5, “There are people I feel close to in this community”). Furthermore, 100% of respondents (20 out of 20) strongly or somewhat agreed with all but two statements (5, “There are people I feel close to in this community,” and 7, “There are things that I can do in this community for fun in my free time”). For a detailed breakdown of the survey responses, see Table 3.1 and Figure 3.7.

Table 3.1: Adapted Community Integration Measure Responses (*n=20*)

	Always agree	Sometimes agree	Neutral	Sometimes disagree	Always disagree
I feel like part of this community, like I belong here.	19	1	0	0	0
I know my way around this community.	17	3	0	0	0
I feel that I am accepted in this community.	18	2	0	0	0
I can be independent in this community.	19	1	0	0	0
There are people I feel close to in this community.	15	3	1	1	0
I know a number of people in this community well enough to say hello and have them say hello back.	19	1	0	0	0
There are things that I can do in this community for fun in my free time.	16	2	2	0	0

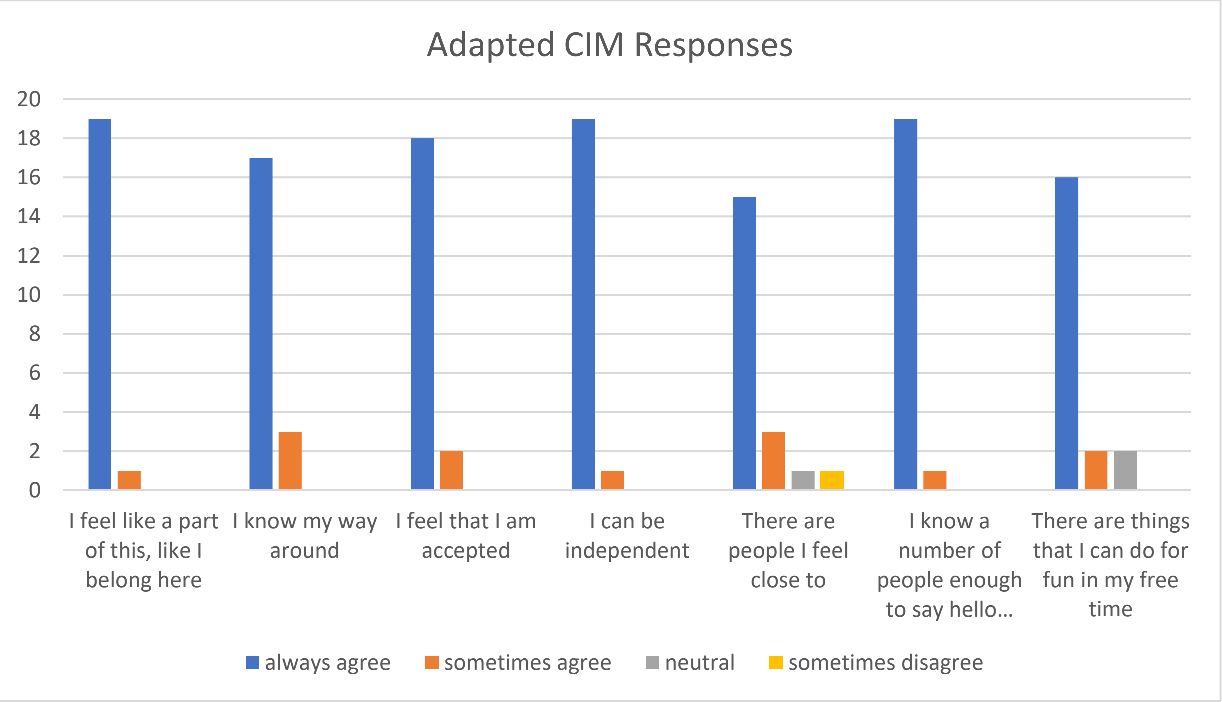

Figure 3.7: Bar graph depiction of responses to adapted Community Integration Measure.

While I do not claim that these results are representative of all the people who frequent Rancho, many considered Rancho a special place, some considered it their home away from home; others considered it family. In the next section, I demonstrate how this sense of community forms as a means of daily practice (disability habitus) in everyday language.

Linguistic analysis: Paternalism and prideful reflection

One example of the sense of community that can spring from the creative efforts of the disabled folks at Rancho is the tetra-meetup that Daphne, a peer mentor supervisor, planned. She intended to have a space where food was served so that newer patients could meet those who had been living with higher level spinal cord injuries for a long time. This gathering would be a gathering centered around food, with the underlying intention of creating a space for peer mentoring to happen, and relationships to be forged, thus enhancing and thickening the sociality. One of the occupational therapists who helped Daphne organize this event decided to add the challenge of having the quadriplegics cook (this would make it an occupational therapy activity, thus justifying the buying of food).

On the day of the meetup, occupational therapists had purchased burgers, buns and hot dogs for grilling in Rancho’s OT kitchen. They also bought celery and carrots for the group to chop and eat with ranch dressing. They had pulled out their adaptive cooking tools, which included a cutting board with long nails sticking out (to mount the food to be chopped). They also had knives with specialized handles that helped the quadriplegics who might not be able to close their hands to get a good grip. One interlocutor, Papi, showed up with a special instrument that he used for grilling. It was a hook mounted on a long piece of wood that made it easier for him to control the food on the hot surface of the grill. There were about 6 quadriplegics that showed up, family members and friends, and a handful of occupational therapists there to stage the event.

This gathering was not uncommon at the hospital. Disabled people were often in situations where they joined together to hang out with clinicians around, milling about, ready to be called in to help, or invited into a conversation. Perhaps because people who use wheelchairs are at similar eye level, or perhaps it is because it was part of the disability habitus, the wheelchair users often interacted only with each other, occasionally inviting others to join in on their conversations. I had given a recorder to one of my peer mentor interlocutors to carry with him as he pushed around the meet-up. My intent was to gather the natural conversations in this setting, thus better understanding what this thick sociality looked like. In the remainder of this chapter, I analyze transcripts from these conversations that demonstrate the components of that thick sociality, and I put them in dialogue with the different theories of community from which I build (rehabilitation, anthropology, and sociolinguistics). I look at conversations in terms of their form, content, and participation to shed light on the types of relationships that are forged in these settings.

The first transcript is a conversation between Papi, the peer mentor, and Amadeus, an interlocutor who had his spinal cord injury for ten years but was currently working with Rancho OT to learn how to cook, a skill he had not pushed himself to undertake until recently. Amadeus' wife, Raeni, and I would occasionally participate in the conversation. Before the excerpt, Papi had been talking to one of the newer outpatients about grilling him and encouraging him to try it out.

Transcript 3.1: Prideful reflection

Papi	He's gri:llin by himself
	<Amadeaus explains to Raeni what Papi is referring to>

3 Papi He’s over there grillin by himself for the first time.
4 Amadeus It’s a good feeling
5 Papi It’s a good feelin=
6 Amadeus =Yeah.
7 Papi Right?
8 He was like, “No, I’m not sure.”
9 I’m like, “you’re gonna grill today bro.”
10 Raeni I love it=
11 Papi =And now he’s stuck over there, he’s like “what do I make?”
12 Raeni I love it
13 Papi That’s priceless right there.
14 Molly So it’s a good feeling when you grill by yourself, huh?
15 Papi I mean, being so limited in what we can do and bein-
16 at least being in control of SOMETHING like that?
17 You’re part of the (.) event. I mean, you’re like doing YOUR part.
18 (2.5) That’s what it’s all about.
19 Raeni That’s right! That’s right!
20 <indecipherable response>
21 Papi Cause like, (.) seein is believing
22 Like, I can’t move my hands, (.) I can move my arm not my hands.
23 And I served up some pretty good burgers and dogs there.
24 Raeni H@@@@@
25 Papi And toasted some bu::ns.
26 Raeni That’s right! That’s right!

The content of this this linguistic exchange demonstrates the parameters of this disability community. Papi, who is a peer mentor and has been disabled the longest demonstrates his knowledge of disability habitus by initially having encouraged the newer quadriplegic (the object of the conversation) to grill. He also reflects on his expertise (lines 23 and 25), by commenting on the quality of the burgers and hot dogs he can produce, despite his impaired hands (line 22). Furthermore, he demonstrates a sense of paternalism with his reported speech (Voloshinov 1973), or constructed dialogue (Tannen 1989), (lines 8 and 9), when he tells the newly disabled person that he will be grilling today. The expert-novice dynamic is part of the disability habitus as those who are living with new injuries learn from others who have been living with impaired bodyminds for years and have figured out how to do tasks, such as cooking. The transcript demonstrates rehabilitation that incorporates community integration in the sense that, through participating in the expert-novice dynamics of the relationship, a person is well integrated. The reported speech provides an example of the social relationships and support, in this case in the form of encouragement, that make up the community. Schegloff asks ‘‘whether human sociality is a matter of knowing together or doing together” (2006, 73). In this example, ‘doing together’ (grilling) is ‘knowing together’ (learning a disability habitus). There can be no separation of the practice of living and functioning in a bodymind and the knowledge of how to use that bodymind.

From lines 15 through 18, Papi explains to me to why the act of participating in the activity of grilling is so fundamental to a sense of self (he de-personalizes, which makes it more general by using the second person pronoun). He explains that participating in this way makes a person a part of the event. Thus, while the grilling provides sustenance for bodyminds it, perhaps more importantly, makes someone feel a part of the community. This affective connection to the event is enhanced by the fact that an impairment has the potential to strip away a person’s typical social role in their community. So, while participants implied in the interview that Rancho was not a full community or was merely a stepping-stone on the way to returning to community, this transcript provides evidence that it truly is a community into which people are integrated as they take on a disability habitus.

In the next section, I turn to anthropological theories of community to shed light on the structure of the conversation as a daily means through which the community (and the disability habitus it entails) are structured (Goffman 1956; 1963; 1981).

Community in social sciences

So how, exactly, have social scientists envisioned community? Studies of sociality, community and belonging have a long history of interest by social scientists and philosophers. Delantey (2010) and Jansen (2020) trace studies of community in Western scholarship to Greek philosophers (e.g. Plato and Aristotle), who tend to conceptualize humans as participants in community through their participation in public life. In broad strokes, social science in the wake of capitalism has pointed to the ways that the forces of capitalism, industrialization, and modernization have dislodged forms of community (e.g. Durkheim 1984; Marx 1887; Weber 2002). The critiques leveled by these scholars have been influential in the anthropology we know today, which identifies the de-centralization of community. Such scholars have pointed to shifts towards modernization, neoliberalism, and globalization, which have induced a sense of fragmentation and social isolation (e.g. Appadurai 1991; Clifford 1992; Delanty 2010; Ortner 1997), including the 'deteritorialized' biopolitical spaces of disability under neoliberalism (Mitchell and Snyder 2015). Scholars have also examined the ways imaginations of shared identity of non-contiguous members are influenced by and influence political and social structures (Anderson 1983). Yet, it is an isolation in which a need for solidarity in community springs (Delanty 2010). From the hierarchical sets of relationships that govern spaces, emerge translocal sensibilities, communication, and a slew of networks that constitute communities (Gupta and Ferguson 1992).

Studies of disability communities have hinted at the way forces of neoliberalism tend to de-center communities (Gupta and Ferguson 1992, etc.), while simultaneously creating more opportunity for a type of biosociality (shared identity among people with disabling conditions, such as genetic disorders) predicted by Rabinow (1996) (e.g. Block et al. 2011; Evans et al. 2020; Friedner 2010; Jackson 2000; Mitchell and Snyder 2015; Rapp and Ginsburg 2001; 2011). For instance, Zola's account of rehabilitation discusses the way his visible disability made rich relationships with other disabled people possible, because they felt that they could open to someone in their own "tribe," in the words of Garland-Thompson (2017). The particular rehabilitation hospital in which Zola spent his time was run by a nongovernmental organization.

Similarly, Bethel, a facility in Northern Japan for people to learn how to live with mental illnesses, such as schizophrenia, successfully created community among disabled people (Nakamura 2013). Many with mental illnesses make a pilgrimage to Bethel and, sometimes stay for ‘recovery’ due to its success of forging community. It is through experiencing community and personal relationships that participants learn how to function in daily life with their disabilities. This approach challenges Western medical values of autonomy. Rather, through interdependence, communicating and coordinating with others, many patients reach a level of healing not afforded through bio-medical practices.

The affordances of community were apparent in the paternalistic sensibilities held by solidarity Amadeus and Papi, who have lived with disabled bodyminds for longer than the newly injured person who was grilling for the first time. In another segment of the exchange between Papi and Amdeus, Papi suggests to Amadeus his idea for a humorous and informative YouTube show about quadriplegics cooking. My field notes indicate that Papi is sitting next to both Amadeus and Amadeus’ wife, Raeni, but he originally only addresses Amadeus until Amadeus makes an effort to include Raeni in the conversation.

Transcript 3.2: Two quads grillin

1	Papi	I’m -I’ve always had this project in mind, but two quads GRILLin.
2	Amadeaus	(.) We should DO that [ma::n
3	Papi	[I’m serious. You and me.
…		
5	Papi	I’ll be like “what’s on the a- menu today?”
6		And you’ll be like “uh today I’m doing my Greek (.) uh chicken kabobs
7	Amadeus	That’d be coo:l=
8	Papi	=Then-then you- you and me would help each other.=
9		=We’d have one of these on our laps?
10	Amadeus	Definitely.
11	Papi	And I’ll have one thing, you have the other,
12		And then, “alright it’s MY turn, get off the grill man.”
13		“Stop touching the food!” You know what I mean?

14 Amadeus Ye@p
15 Papi Make it comical.
16 “Man you burned my chicken [again? What the hell?”
17 Amadeus [h@@
18 Papi “Go to the store and buy me some new ones.” <laughter in voice>
19 Amadeus Na, we should DO that.
20 Papi Isn’t that funny?
…
22 Amadeus <explains to Raeni what they were talking about>
23 Raeni I LI:KE THAT.
24 Papi Droppin the foo:d on the floor
25 Raeni H@@@[@ Whoops!
26 Papi [We’ll be like – we’ll be like “30-30 second [rule
27 Raeni [30 sec- H@!
…
28 Papi And then when the 30 seconds run out you go BERR! <sound of a buzzer>
29 Raeni H@@@
30 Papi And then we’ll call our-our attendant over to pick it up.
31 I mean, sky’s the limit ma:n.

The content of this exchange, which is rather humorous if one feels comfortable laughing at disability, is performative of a disabled identity. Amadeus and Papi sketch their performance for a YouTube show. Rather than succumbing to the stigma of disability and the lack of functionality that is assumed, they imagine their future in which they are celebrities. The main goal of their show would be to create a humorous setting in which their functionality (their ability to grill) is on display. The ‘humor would be derived from their snappy personalities (e.g. “get off the grill man” in line 12 “stop touching the food man” in line 13; “man you burned my chicken again” in line 16), the way their disabilities impact their cooking (e.g. “droppin the food on the floor” in line 24), and their responses to their own disabled cooking (e.g. “we’ll be like,… 30 second rule” in line 26). Such ‘dark’ humor about disability is a way of shifting negative valuations about disability and forging relationships with others with similar experiences (Bloom 2019). It accomplishes the same function as the “gallows humor” that Açıksöz describes among disabled Turkish war veterans. He writes:

> The gallows humor I encountered... entails not an individual denial of vulnerability but rather an intersubjective process that transforms the negativity of traumatic loss into a therapeutic force by voicing vulnerability in a humorous way. Coming from politically consecrated yet socially stigmatized bodies, the laughter produced through gallows jokes... can be voiced only in the presence of those sharing a particular fleshly intimacy. And yet it also produces this intimacy, both normalizing and communalizing the experience of having nonnormative bodies (Açıksöz 2020a,131).

In addition to the content of the interaction, the interactional narrowing of who can legitimately participate in this imagined YouTube comedy, exemplifies how Rancho's disability community is built on a micro-level. It is not a coincidence that Papi addresses only Amadeus, at first, for his musings on his future show. Papi makes it clear that Amadeus is a ratified participant through addressing only him (line 1). While Raeni is sitting within earshot, she is not addressed and relegated as an overhearer until Amadeus invites her into the conversation (line 22). Even though she would understand the quadriplegia jokes (as her husband is a quadriplegic), I suggest that Raeni is a not ratified as addressee because her able-bodymind figures her outside of the typical social networks that are formed within Rancho's thick sociality. While she can be figured into that framework as overhearer and eventual direct participation in the conversation, it was not Papi's immediate instinct to address both Amadeus and Raeni.

The structuring of this conversation to involve disabled folks interacting mainly with other disabled people was enhanced by the overall context of the barbeque, which was set up for the quadriplegics to meet. Occupational therapists and other clinicians were there but remained largely quiet unless invited into conversations. They helped stage the event (by getting the kitchen tools requested and jumping in if someone asked for help), but they tended to let the event center around those with disabled bodyminds. This arrangement seemed to flow from an institutional ideological to support disabled folks to build the meaningful lives they wanted. In this event, attendees enjoyed building relationships with people with similar disabilities. As conversation analysis has demonstrated, the structure of participation in conversations builds, reinforces, and reifies social order (e.g. Goffman 1956; Goodwin C. 1981; Goodwin and Heritage 1990; Goodwin M.H. 1990; Schegloff 1990). The conversation between Amadeus and Papi generates sociality that exists around disability.

Thus far, I have argued that community integration, a rehabilitative concept, is happening at Rancho and I have demonstrated that one of the ways it forms is when disabled folks gather together. In the next section, I examine linguistic anthropological and sociolinguistc concepts of the speech community(Alim 2004; Gumperz 1968; Irvine 1987; Kroskrity 1982; Morgan 2001; Rampton 2010; Romaine 1982; Slotta 2012) and communities of practice (Bourdieu 1977, Bucholtz 1999; Eckert and McConnell-Ginet 1992; Lave and Wenger 1991) as means of explaining the components of Rancho's thick sociality). I demonstrate that both concepts are useful but need to be expanded to describe the rich community at Rancho.

Communities and sociolinguistics

Two main approaches to community in anthropology and sociolinguistics, fields interested in the role that language plays in group-differentiation, have been communities of practice and, its theoretical predecessor, speech communities. Communities of practice are groups of people who come into contact regularly based on a shared engagement (Eckert and McConnell Ginet 1992; Lave and Wenger 1991; Mendoza-Denton 2008; Meyerhoff 2002), a theoretical concept with roots in practice theory (Bourdieu 1977; 1990b). An interesting study that examines a disability community of practice is Standal and Jespersen’s (2008) research on a wheelchair skills class. Standal and Jespersen note that those who had more advanced wheelchair skills were effective teachers for their less advanced peers, who valued their knowledge more than able-bodied and able-minded medical professionals. Disabled peers had more credibility to participants because of their lived experience with disability (see also Rymes 2001 the credibility among high school peers of formerly incarcerated students). The mentees came to place a higher value on knowledge based on the common experience of disability. The exchanges that I have analyzed thus far speak to this sense of trust in learning that is gained through disability practice. In my field notes from the meet-up, I indicated that quadriplegics with more cooking experience, whether they were peer mentors or not, would jump in with advice for the newly injured patients. As I will demonstrate in the analysis of the following exchange, the disabled folks at Rancho tend to have an easy time opening up about disability-related struggles to other disabled people. Indeed, this is one of the ways that the thick sociality at Rancho helps people, especially those who are newly injured, build a disability habitus.

Standal and Jespersen (2008) note that patients described peer mentors as using ‘everyday language,’ as opposed to the medicalized language used by rehabilitation professionals. I suggest that the everyday language found in their study is evidence of a vernacular building a speech community. For sociolinguists, communities of practice are a subset of speech communities, groups of people with their own distinct way of speaking, especially a shared communicative repertoire (Gumperz 1968). I follow Ochs and Solomon, who extend “the notion of repertoire to refer to repertoires of social coordination and to the idea that members of communities are equipped with partly overlapping and partly distinct repertoires of social coordination, which are organized by individual and sociocultural lifeworlds” (Ochs and

Solomon 2010, 72). In doing so, I conceptualize the speech community at Rancho as not one that shares a specific language, especially since Rancho is a multilingual setting, but one that tends to center around ways of communicating with each other. For instance, disabled people adopt a disability habitus in which it is appropriate to initiate conversations with other disabled folks only because they are disabled. This might be unacceptable outside of the hospital. Furthermore, as the next exchange will demonstrate, there is a level of vulnerability and intimacy that is acceptable among disabled people at Rancho, even if they do not know each other well. Papi approaches Joseph, a quadriplegic inpatient with whom he is somewhat acquainted and begins a conversation with him about his rehabilitation.

Transcript 3.3: How have YOU been?

1	Papi	How have YOU been?=
2	Joseph	=Ok <falsetto> (.) It's alright. (.) Still different. h@@
3	Papi	Ok. How's you're everyday life been? (.)
4		Feel like you're getting stro:nger a little bi:t?=
5	Joseph	=Yea[h. (.) I am.
6	Papi	[Yeah?
7		Bala:nce is a little better ma:ybe?
8	Joseph	Mhm.
9	Papi	Yeah. (.)
10	Joseph	It IS getting (.) better. (.)°It's just really slow right now.°
11	Papi	Little by little you know? [When you're si:ttin in be:d
12	Joseph	[I'm a really impatient person.
13	Papi	Yeah
14	Joseph	I'm just (impatient). (.) So it's annoying [how slow
15	Papi	[yeah I know I know.
16		I tell people, "you weren't patient before you were here,
17		Now you're forced to be patient"
18	Joseph	Yeah (.) (You're) forced to [do that.
19	Papi	[You HAVE to You HAVE to-
20		It's something you have to learn how to wo:rk with?
21		And it's hard the transi:tion? cause we're like (1.3)
22		One step right awa:y sometime:s (.) and we get frustra::ted?
23	Joseph	Yeah
24	Papi	Especially when we're young you know?
25		[When we're twe:nty?

26 Joseph [Yeah
27 Papi You-you can’t be waitin. You know, we like bang bang quick!
28 Joseph Yeah (1.6) It’s work though
29 Papi It’s-it’s part of reCOVERY you know?

In this conversation, which begins with Papi probing to find out how Joseph is doing, Joseph does not go into much detail when asked “how have you been” (line 1). Instead, he delivers short utterances, full of pauses, likely related to the fact that he is delivering a dispreferred response, rather than an affirmative response that, everything is going well. Papi scaffolds his answer by providing a topic on which Joseph can focus, “balance is a little better maybe?” (line 7). In doing so, he helps Joseph orient to the disability habitus that balance is something to attend to in a rehabilitating bodymind. Indeed, balance becomes a topic of many conversations among disabled people at Rancho, who compare their levels of injury and their ability to balance.

In lines 10 and 12, the problem for Joseph - the reason for his terse answers - begins to unfold when he explains that rehabilitation is taking a long time and he is impatient. While Joseph does not comment on his emotional state, the juxtaposition of his self-evaluation as impatient (line 12) as a response to Papi’s probing questions about how everything is going suggests that this utterance, “I’m a really impatient person,” is loaded with affect. At least, that is how Papi seems to interpret it as he begins to launch a life lesson for Joseph. As Papi explains that spinal cord injuries will force a person to experience patience - which orients Joseph to the slow temporality of the disability habitus - he eventually shifts from second person pronouns (lines 16, 17, 19 and 20), indicative of the expert-novice dynamic explained earlier, into first person inclusive pronouns (lines 21, 22 and 25). This shift into the inclusive ‘we’ is a means of structuring Joseph as belonging in the disability community that knows intimately the struggle of rehabilitation and living with a disabled bodymind after leading an able-bodied life. It is also an interactional strategy for Papi to address the affect that underlies Joseph's responses to his questions. The interaction becomes intimate, and Papi responds to Joseph's vulnerability to showing that he, too, is vulnerable. This interaction exemplifies the ease with which vulnerability can be a topic of conversation - a part of Rancho's disability habitus. If we consider a speech community in the expanded sense that Ochs and Solomon call for, we can see this interaction as an instantiation of a speech community. The interlocutors' possibilities for co-membership are dependent upon not only a speech repertoire but also a shared sense of expectation for such a conversation. Papi demonstrates that it is alright to be vulnerable and communicate vulnerability without ever saying that directly. This kind of conversation could have a healing impact on Joseph's disability habitus. As Joseph is a newly injured patient, it is one of the few instances in which a discussion of psychological difficulty and sadness is acceptable. In the words of Açıksöz (2020a, 125): "Through the discourse and reality of shared loss, the negativity of pain and suffering becomes a therapeutic force that draws the members of these communities into an intersubjective field of nonmedicalized healing."

These interactions provide yet another piece of the lifeworld that builds a strong sense of community at Rancho. Yet, if we consider this only along the lines of communities of practice, we run into theoretical issues. Joseph is not directly engaged in the practices that have united all the other quadriplegics: grilling. He seems to have no interest in this practice, yet Papi approaches him and deepens a social relationship with him. This bond-forging conversation ultimately becomes a thread in the tapestry of disability community. In her critique of anthropological approaches to community, Amit argues that community exists in collaboration and practices, but also through a sense of belonging that exists simply in co-presence (Amit 2020). The idea that co-presence is enough to create community, whether or not people are ambivalent about engaging in shared practices, is important to keep in mind with the community at Rancho. Many participants told me that simply being there, in the presence of other disabled bodyminds, is enough to make them feel included. Thus, while conventional communities of practice are influential in my own theorization of community, this notion needs to be revised to incorporate a sense of community that allows people simply to occupy the same space physically, affectively and in their bodyminds.

Conclusion

In this chapter, I have proposed the concepts of thick sociality and disability habitus to frame my discussion of community at Rancho. When I first arrived at Rancho, this sense of community was everywhere I looked. It is also present in the conversational exchanges that I have documented, including responses to the adapted CIM and transcripts of a “quad meet-up” at the hospital. The quantitative results from the adapted CIM indicated that disabled folks at Rancho conceptualized the milieu there as a community into which they were integrated. The conversational exchanges among Rancho folks demonstrated some of the nuances of that community, including hierarchies of knowledge, laser-focused selection of conversational partners around common ground topics , and the sense of belonging through mere co-presence. I suggest that there is a direct historical connection between the poor farmers that give the institution its grounding spirit and the thick sociality that remains there. In the next chapters, I continue to explore this sociality through disability expertise (Chapter 4) and agency (Chapter 5).

CHAPTER FOUR - Disability expertise as "an open book:" Peer mentors talk intimacy, taboo and transgression

Introduction

At 10:55 am on a Wednesday in December 2017, I arrived at the Activity Room in Rancho's adult SCI unit. I was 5 minutes early for the daily Starting Out Class meant to educate patients about different issues associated with SCI. The room's warm, dull colors from the taupe floor tiles and the pinkish beige walls were broken by the pop of color on the nurse's cartoon scrubs, as she set up the power point for the day's class – bowel care after SCI.

Inpatients began to arrive in the Activity Room, and the nurse encouraged the inpatients to arrange themselves in a circle, which was an awkward task for the group, as many did not yet have a concept of spacing in their wheelchairs. The intended circle soon morphed into a misshapen lump around the periphery of the room. Eventually, a peer mentor, an employee with a disability hired by the hospital to provide perspective on the lived experience of disability to patients, rolled his way into the room in his power wheelchair. Each participant in the misshapen lump was prompted to introduce themselves with their names and their level of injury. Forest, a C4-incomplete quadriplegic, followed the greeting formula. His identification as having a C4-incomplete injury referred the section of his spine (C for cervical) where his injury was located, the number of his vertebra, counting from the highest vertebra down (4), and the degree of severance in his spinal column (incomplete). Forest followed his standard SCI explanation by telling the class: "we [peer mentors] are open books."

In my twenty months of ethnographic fieldwork with peer mentors and community members with SCI at Rancho, I heard this phrase more times than I could count. The phrase was used to invite patients to ask questions about life with SCI, especially on topics that seemed taboo, such as bowel and bladder care and sex. Learning about these topics is an essential part of life with SCI, as bodily messages for functions like bowel movements, urination, and sex typically travel from the brain, through the spinal cord. When a person's spinal column is injured, there is a chance that such messages might be disrupted. Often, people with SCI need to learn how to regulate these functions, sometimes with the help of assistive technology. For instance, people may need to stimulate bowel movements through suppositories, or people may need to urinate using a catheter. Beyond simply biological necessity, orienting to bowel, bladder, and sexual functioning with a SCI is re-orienting to a sense of self. Bodily fluids and waste are abject: our relationship to excrement, urine and sexual fluid is a social orientation to self (pure) and other (defiled) (Douglas 1966; Kristeva 1982). Learning to have control over bodily functions is not simply a means of biopower through self-control and moderation (Foucault 1990) (as discussed in Chapter 2); it is also a means of learning where the boundaries of the self and abject are drawn.

The opening vignette of Ralph's analysis of the victims of inner-city violence in Chicago who cope with psychological and physical injuries hints at the abjection with which people with SCI must reckon. In Ralph's account, during an assembly on gang violence, a paralyzed man, who was attempting to convince an audience of high school students to avoid gang membership, performatively enacted this abjection. In front of the assembly, he pulled out his empty catheter bag connected to a long plastic tube. The man describes how he inserts this tube into his penis to drain his bladder. The audience gasps and squirms with such a vivid explanation and the demonstration of the medical equipment. (Ralph 2014). One of the points Ralph makes with this description is that the victims of inner-city violence used their disabled bodyminds as a display of the negative consequence of gang involvement (Ralph 2012; 2014). Alternatively, this dissertation has outlined a community with a very different relation to disability. Disabled peer mentors who explain that they are an “open book” invite newly injured patients to explore vulnerable topics through their own experience. For instance, Kyle, a peer mentor, described his role this way:

Transcript 4.1: Telling the truth

Kyle A good mentor (.) is always- I mean, tells the truth- always tells the truth.
Like I always say in the classes too,
Like, “I’m an open book I’ll tell ya anything man.”
Like, I’m not shy? (.) Um like, you know you have-
Like you have ANY questions about (.) sex, bowel program, bladder, this, that
I tell you anything (.) you know what I mean?
Like I WON’T lie to you, I have NOTHIN to lie about.

Kyle positions sharing his experience with questions about taboo topics as a matter of honesty. In the excerpt, he uses the notion of truth to characterize his experience with disability, and his willingness to share that experience. Through his language, he builds an epistemic stance, the “truth value of a proposition and the speaker’s degree of commitment to it” (Irvine 2009, 2). His orientation to the truth of taboo bodily functions with a SCI is, furthermore, a means of performing an attitude towards his disability, a kind of affective stance. Throughout his talk, he builds an attitude of disaffectedness towards taboo topics of disability. Though such topics of abjection might be vulnerable and uncomfortable for some, as demonstrated in Ralph’s vignette, Kyle invites this vulnerability in order to be a “good peer mentor.” Finally, in this metalinguistic utterance, he imagines a mentee to whom he is speaking. Thus, his orientation to this imagined person is yet another stance, in which he takes on an expert position due to his disability experience. All these stances that Kyle builds, towards his own truth value, his bodymind, and an imagined disabled mentee, are wrapped up in his explanation of being a virtuous “open book.” Unlike the openness that invited a sense of abjection described by Ralph, being an open book at Rancho means orienting newly injured patients to an experience of disability that is not stigmatizing, but, rather, orienting towards a hopeful future. While Ralph examines the way injured gang members highlight the stigma and difficulty of their impairments to convince young people not to engage in gang violence, this chapter examines discourses of disability and taboo that build community through the shared experience of abjection.

Describing themselves as open books is a means for peer mentors to signify their extensive knowledge of life with a disability. This chapter explores disability expertise, an expertise that people learn through the lived experience of disability (Hartblay 2019, 1). Disability expertise is:

> the particular knowledge that disabled people develop and enact about unorthodox configurations of agency, cultural norms, and relationships between selves, bodies, and the designed world. Disability expertise is a descriptive domain, that is, a container into which ethnographers might enumerate observations about how disabled people enact personhood and moral agency in diverse cultural settings.

In this chapter, I expand on moments in which disabled folks provide meta-commentary on their own disability expertise, or when they socialize other disabled people into this knowledge, thus orienting them to Rancho's disability community, and the attitudes towards disability embedded in that context. The theoretical goal of "enumerat[ing] observations" in the domain of disability expertise is to discern the way such knowledge is a deeply rooted aspect of disability habitus. More generally, the goal is to point to moments in which disability is enacted through a relation to a rich social world of ideas, things and people. I draw on linguistic anthropological approaches to stance, which I use interchangeably with footing (e.g. Bucholtz 2009, Du Bois and Kärkkäinen 2012, Goffman 1981; Irvine 2009; 2011; Jacobs Huey 2006; McIntosh 2009), especially those considering stance taking as a multimodal process (C. Goodwin 2007; M.

Goodwin 1990; 1998; 2006; M. Goodwin and Alim 2010). Stance is a valuable framework for analysis because, as Mendoza-Denton (1999, 273) explains:

> On the local level, stances display interactional identities as speakers align or disalign with one another by expressing agreement or disagreement with one another's propositions. On the wider social level, stances reflect and construct aspects of social identity as speakers take up positions associated with particular social categories and groups.

In some cases, I expand on the relationship between stance and the participant frameworks of the interactions.

To demonstrate disability expertise, Hartblay explains how her interlocutor, Anya, a woman with a muscular disorder, served her tea. Hartblay, who carried out fieldwork with disabled folks in Russia, visited her interlocutor in her apartment. Cultural norms dictated that Anya serve Hartblay some tea during this visit, however, her impairment prevented her from turning on the kettle and unwrapping the cookies needed for such a show of hospitality. Therefore, “without missing a beat” (Ibid 2019, 4) her interlocutor began to explain to Hartblay how to get the tea ready. Hartblay’s claims that Anya’s seemingly automatic instruction is a form of disability expertise; rather than allowing Hartbaly to feel a sense of anxiety when she realized that tea was expected, but Anya’s disability prevented her from making tea, Anya dispelled Hartblay’s potential anxiety with her quick and direct instructions. In other words, Anya was adept at experiencing someone else’s perception of her, and the impact that her disability would have on an interaction and had developed strategies to navigate such delicate situations.

This focus on the intricacies of daily interaction with and among disabled people has incredibly rich potential for analysis. Many scholars have demonstrated that disability can have an immense impact on the course of interactions (Capps and Ochs 1995; Garland-Thomson 2009; Goffman 1963; C. Goodwin's 2004; 2010; Ochs 2015; Robillard 1996). Navigating the social world with a disability requires an awareness of how one is perceived by others. Such an awareness is similar to what DuBois described as "double-consciousness" (W.E.B. DuBois 1903), a "sense of always looking at one's self through the eyes of others, of measuring one's soul by the tape of a world that looks on in amused contempt and pity" (W.E.B. DuBois 1897). For disabled people, who navigate the world in non-standard ways and for whom there exists a dearth of potentially stigmatizing ideologies, awareness of how one is perceived is an essential aspect of disability expertise. Approaching disability expertise from the linguistic purview of stance sheds light on the way people position themselves in relation to others, as well as attitudes about disability.

The insights related to this chapter are drawn from audio recordings of SCI Starting Out Classes (lead by at least one peer mentor and a clinician) and peer mentor training sessions. Due to IRB regulations, it was difficult for me to collect audio recordings at the hospital during most of my fieldwork. I was, however, able to gain permission to record the interactions that I analyze in this chapter. In instances when I could not record or did not feel it was appropriate, I had permission to write field notes. Therefore, several examples come from field notes of interactions as they occurred. These were moments in which disabled folks were cultivating a disability habitus through daily encounters. This chapter expands on the institutional and community framing of these encounters (see Figure 4.1). I argue that an essential part of the disability habitus is the orientation towards life as *ordinary*. For tasks that seem extraordinary to newly injured patients, particularly learning to both manage and talk about bodily functions, even those which are taboo, like defecating, urinating and having sex, mentors perform subtle shifts in alignment to socialize patients into this habitus. In doing so, they cultivate a safe space in which discussions of vulnerability are frequent. This is socialization into disability expertise, as described by Hartblay. Yet, the interactions occur in the institutional context of a rehabilitation hospital, and involve peer mentors, who wield some degree of institutional knowledge. Thus, the interactions are a blend of what might be described as the "vernacular" approach to disability expertise in Hartblay's example, and a medicalized approach to impairment. Through this socialization, disabled people learn how to 'do' disability.

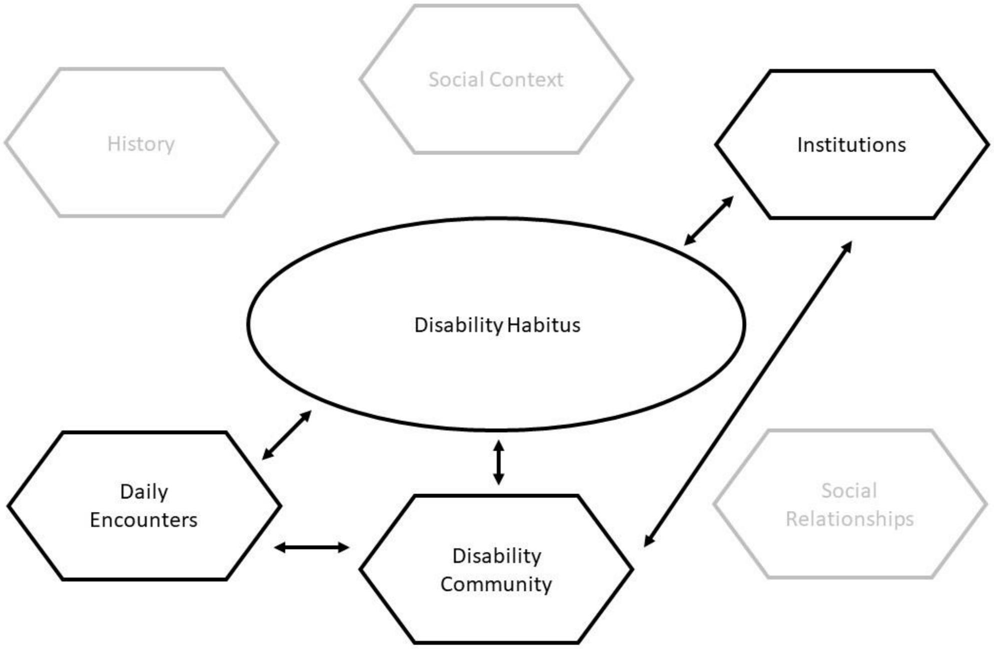

Figure 4.1: Contours of disability expertise. The image depicts the interacting facets of the disability habitus with which this chapter deals: daily encounters; disability community; and institutions.

What is peer mentoring?

While other parts of this dissertation focus on both peer mentors interacting with hospital community members, this chapter focuses on peer mentors, who, interestingly, have formal disability expertise, particularly through familiarity the Peer Mentor Training Manual

(KnowBarriers 2018). Mentors work or volunteer to teach about life with a disability. Their position privileges their ability to socialize others into disability expertise. Additionally, peer mentors are typically paid for their communicative competence (Carr 2009; Hymes 1972; Irvine 1989). Much like the griots described by Irvine (1989), who are paid for their verbal skills but who come from a lower caste in society, peer mentors are lower in the hospital hierarchy. They are paid low wages, if they are even paid at all. Furthermore, their position depends on an informal knowledge of living with disability. They are thus, "hailed as a particular kind of institutional subject and respond… as such" (Carr 2009, 317). Through cooperation in the communicative frameworks at the hospital, mentors indicate their "joint values," in which the "interests of the organization and individual member coalesce" (Goffman 1961, 178).

Despite their lack of formal schooling, they receive peer mentor training, which includes about fifteen hours of instruction. During this time, peer mentors are familiarized with their duties. Like social work practices, talk plays a crucial role in rehabilitation, "in which healing people commonly involves reworking their relationship to language" (Carr 2009, 318). Peer mentors are trained in several communicative techniques drawn largely from counseling. For instance, they use formats such as Active Listening, a specific mode of listening from counseling and conflict resolution. They are also trained to identify the five stages of grief and use OARS, an acronym for open-ended questions, affirmations, reflective statements, and summarizing (KnowBarriers 2018). Linguistic anthropologists have acknowledged that communication is more than simply "the forceful gush of humanly shaped, vibrating air" (Irvine 1989, 260). Instead, it is a deep web of meaning that encompasses not only utterances but also bodily orientation and movement (M. Goodwin 1990; 2017; Kendon 1985), as well as ever unfolding construction of turns and turn-taking (Goodwin C. 2017; Sacks et al. 1978; Schegloff 2007; Schegloff and Sacks 1973). Peer mentors themselves have been socialized into and through an array of forms of communication, which they are encouraged to utilize as experts. They are expected to be attuned to the full range of communication that goes beyond the literal meaning of utterances. This is what BJ, one of the two founders of KnowBarriers and the peer mentoring program calls “reading between the lines.” They are also trained to “accidentally” demonstrate skills that might benefit patients in a technique called modeling. For instance, David, a mentor with a T-6 level SCI, told me that he often will make it look as though he has accidentally dropped his pen in front of patients with similar injury level. They can observe him pick it up, while maintaining his balance in his wheelchair, despite his lack of core stability. Additionally, as many of the peer mentors are both Spanish-speaking and English-speaking, they may be called on to serve as informal interpreters for Spanish-speaking patients. They work in a variety of settings around the hospital: SCI Starting Out Classes; inpatient in-room visits; the SCI outpatient weekly transition clinic; the resource desk, stocked with pamphlets on many aspects of life with a disability, as well as information about Rancho; SCI occupational therapy and physical therapy appointments (both outpatient and inpatient); the Don Knabe Wellness Center, a gym on campus where anyone can purchase a cheap membership to work out; and SCI support groups. At each point in these settings, peer mentors attempt to provide solidarity and resources for disabled people who may benefit from guidance and support.

This chapter explores the main function of peer mentoring, which, I argue, is to serve as an embodiment of patients’ stance towards an ordinary future. Through communication with mentors, patients have the option to imagine themselves in the future, living ordinary lives, with ordinary functions, as basic (and taboo) as bowel, bladder and sexual functioning - an imagination that might seem completely out of reach for someone coping with a new SCI.

Greetings: How to talk about SCI

The most obvious community socialization practice was greetings among peer mentors and inpatients, especially in Starting Out classes. Greetings are an important part of the “communicative competence necessary for being a member of any speech community (Duranti 1997, 63; see also Goffman 1967; Irvine 1974; Schegloff 1987). In the greetings explored below, participants may or may not know each other, but they are expected to describe their disabilities. Such descriptions place the interlocutors within a realm of particular social personae (Duranti 1997) linked to the institutional setting of rehabilitation. In each Starting Out class, clinicians usually began by introducing themselves with their institutional role at Rancho. This opening would be followed by a prompt for inpatients to introduce themselves with their names and their level of SCI (what section of their spine, - cervical, thoracic, lumbar, or sacral - the vertebral number, and the degree of injury - complete, or incomplete). For novice inpatients, this moment offered an orientation to the bodymind, and many were unfamiliar with the labeling conventions. Performing a successful greeting entails a person having medical knowledge of their injury, and access to the appropriate vocabulary.

The following greeting exchange in the sexuality Starting Out Class involves an inpatient, Bam, introducing himself to the clinical psychologist, Doctor Alice, and two peer mentors, David and Mariana. The mentors and psychologist regularly facilitate class instruction together. In the segment, Bam is prompted by Dr. Alice to introduce himself.

Transcript 4.2: Scaffolded greeting

1	Dr. Alice	What would be really helpful is- we'll all introduce ourselves too,
2		but what is, um (.) your injury level?
3		Um:, and (.) kind of (.) your main focus right now?
4	Bam	I’m: a L2. (.)

5 Dr. Alice L2?
6 Bam Yeah
7 Dr. Alice Do you know whether it’s complete or incomplete?=
8 Bam =I think they said incomplete (.)
9 Dr. Alice Ok?
10 Bam A:h (.8) My main ↑focus is like (.) basically tryin’a get back on my feet again
11 Dr. Alice Ok (.) Ok, so gettin' (.) recovery and mobility.
12 Bam Yeah
13 David Yep. Same as me. Like (.) sexuality wasn’t (.) the HIGHest priority
14 Like (.) “I wanna (.) get better first?”

Dr. Alice asks Bam to introduce himself with his injury level and his focus, relevant pieces of information for sexuality class. Bam, who has been an inpatient for almost a week, has some experience with these greetings, as he responds to Dr. Alice’s prompt by saying, “I’m a L2” (line 4). Bam self-identifies metonymically as “I’m a L2,” as is typical for people with SCIs. If Bam had no insider knowledge, he might have said, “My injury is at L2,” identifying where in his body he was injured. In this manner, he aligns with the disability habitus.

Soon after, it becomes evident that he has not fully absorbed disability expertise, as Dr. Alice needs to prompt him to complete the greeting by indicating whether his injury is complete or incomplete (line 7). Dr. Alice’s question, “Do you know whether it’s complete or incomplete,” calls out Bam’s greeting as a faultable (Goffman 1981). Bam should have said “I’m a L2, incomplete.” Bam indicates uncertainty about his disability, noting that “I think they said incomplete.” This moment of socialization indicates to Bam that his knowledge of his disabled bodymind (stance) is incomplete. While the psychologist indicates this insufficiency, the peer mentor, David, evokes alignment with the inpatient. Both participant roles have their affordances in this setting.

After a pause, Bam responds to the rest of Dr. Alice’s question, noting his main focus is trying to “get back on my feet again” (line 10). This proposition is interesting, as Bam, who has exclusively used a wheelchair since his SCI, expresses a desire to get back on his feet. While it might be possible that he recovers enough to walk again, the likelihood that he will not rely on a wheelchair for his day-to-day mobility is low. Therefore, his stated desire may indicate that he has not yet fully oriented to his disability. David follows his explanation with alignment in lines 13 and 14. In doing so, he shifts the focus off Bam and onto himself. David aligns his past self with Bam's present self. This alignment is an essential aspect of the participant role of peer mentors.

The next exchange features disabled people who have mastered the SCI greeting. It demonstrates how the greeting has become embedded in the disability habitus for the people with SCIs, all of whom have been injured for years. They demonstrate an ability to appropriately align to their own disabilities and with each other's introductions through their responses (or lack thereof). In the excerpt, from a peer mentor training course, five peer mentor trainees (Miguel, Michael, Just Roll, Vegeta, and Mick) introduce themselves to each other and the three supervisors facilitating the session (Daphne, Kyle, and Jim). All the participants, including supervisors, have SCIs.

Transcript 4.3: Greetings in peer mentor training

1 Miguel Oh, ah- my name is Miguel? I-I have a T8 level injury?
2 And, ah (.) since 1998, May 98 and (.) I came through ↑Rancho (.7)
3 .h um (.) and I'm still here. h@
4 I haven't been at no other hospital for@ my- my @injuries. [°h@° Yea:h.
5 Daphne [°h@@°
6 Nice to meet you
7 <indecipherable collective talk>
8 Michael Uh- my name's Michael T5.
9 Miguel Michael is tha-?
10 Michael Michael, T5. And I, um XX Resource Center?
11 Just Roll Just Roll? Um,
12 Daphne I'm sorry you're name?
13 Just Roll J-Just Roll, a C5 C7 incomplete? Due to a gunshot wound.
14 Daphne How long ago?
15 Just Roll Um:, I got shot back i:n (.) XX. I was 15. And about a week later I was 16.
16 Michael (1.3) I was 17.

17 Daphne You were 17?
18 Miguel Teenagers h@@@.
19 Kyle I was 18
20 Miguel °Woaw°
21 Vegeta Ah, my name is XX. They call me Vegeta.
22 I got injured 2009. Um I’m a T7 complete, spinal cord injury.
23 Miguel 2- in 2- 2009?
24 Vegeta 2009.
25 Daphne What happened?
26 Vegeta Oh. Gunshot.
27 Jim You’re at about 10 years then, now huh?
28 Vegeta Multiple gunshot.
29 <collective pause>
30 Just Roll Multiple you said?
31 Vegeta Huh?
32 Just Roll Multiple?
33 Vegeta °Yeah°
34 Kyle Was yours one time?
35 Just Roll Yeah one time. XX.
36 Daphne XX. I was in a car crash where I broke my C5 and C6=
37 =I shattered the vertebrae and that was it=
38 Kyle =[Me too
39 Daphne [.h ah
40 It only [takes once-
41 Kyle [same for me.
42 Daphne Right?
43 Kyle [Messed up my nose and all that.
44 Just Roll [Car accident?
45 Kyle But other than that, (.) no (.) broken bo:nes, no XX except for my neck
46 <indecipherable collective talk>
47 Mick Mick. (.) Ah (.) got injured in 1992. Car accident. (.) 14. (1.3)
48 C7:: incomplete?
49 Jim C7?
50 Mick Yep.

These greetings are common among peer mentors. They are also common when mentors introduce themselves to inpatients. They operate as a ritual greeting, as the explanations of disability and, sometimes, how the disability was sustained are nearly route. This rote identification of disability validates co-membership within the disability community. Miguel opens the interaction by introducing himself with his name and the explanation: “I have a T8 level injury” (line 1). He does not use a metonym to introduce himself (he does not say, “I’m a

T8”). This is acceptable but not standard. He also follows this greeting with information about his connection to Rancho. Daphne demonstrates alignment to this by mirroring his laughter (lines 4 and 5); however, she does not invite him to provide more information. She closes out his greeting by saying “nice to meet you” (line 6). This indicates to the group that they continue with their greeting, an opportunity that Michael takes up. He simply introduces his name, level of injury, and where he works (in the Resource Center) (lines 8 and 10). The greeting is followed by Just Roll who, for the first time in the group encounter, describes how he was injured (line 13). At this point Daphne invites him to expand on his injury by asking him to specify a date of injury. This expansion of Just Roll’s injury becomes a factor of further alignment during this greeting session. When Just Roll explains that he was 15 when he “got shot” (line 15), Michael expresses alignment with him due to the similar age at which they sustained their SCIs, stating, “I was 17” (line 16). Kyle, a supervisor, also aligns with this by stating his age at the time of his injury, “I was 18” (line 19). When Vegeta introduces himself, he is invited by two supervisors to expand on his greeting, even though he had indicate his name, level of injury, and the year he sustained his SCI. Daphne, in line 25, asks him “what happened,” and Jim adds, “you’re at about 10 years then, now huh.”

What is interesting about these greetings is that they become narratives that expand beyond simply name and level of injury. With each new greeting, more narrative is requested by the supervisors. I argue that the building upon greetings by drawing out narrative details like setting (age of injury) and precipitating event (cause of injury) enfolds participants into a shared lifeworld and empathic intimacy.

Miguel’s self-initiated injury and rehabilitation narrative similarly indicates an affective alignment with Rancho early in the interaction in lines 2 - 4. This affect is apparent in the prosody of his utterance of Rancho in line 2 and his laughter tokens that accompany his explanation of the length of time and commitment to the hospital. The affective stance builds as Michael, Just Roll, and Kyle compare their similar ages of injury in lines 15 - 19. Miguel, who points out that they were teenagers (line 18) utters a quiet “woah,” an utterance loaded with affect. The interlocutors who were injured as teens do not explicitly state their emotions. Rather, their terse contributions, stating simply the age of their injuries, build an affective intensity, leaving experienced and empathic peers to fill in what is elided: that such a life-changing injury must have been difficult to cope with during the formative teenage years.

Empathy heightens through Just Roll’s and Vegeta’s alignment over the cause of their SCIs - gunshot wounds. When Vegeta indicates that he sustained multiple gunshot wounds (line 28), Just Roll takes this up by posing his rhetorical question, “Multiple you said” (line 30). He is eventually invited by Kyle to state how many gunshots he sustained. While the content of their predications concerns the manner of sustaining their injuries, the unspoken aspects of their experiences index the intense emotion embedded in the vulnerable topics of injury and violence. Daphne aligns, using irony to cast the narrative of the car crash that caused her SCI - “I shattered my vertebrae and that was it… It only takes once” (lines 37 and 40). Kyle then signifies his alignment with his ironic twist of fate that caused his SCI, only injuring his vertebra, resulting in his SCI.

The group moves to close out the greeting and begins to shift away from the emotional stance after Mick, the last member in the group, provides his telegraphic greeting and narrative. He provides his name, date and manner of injury, his age at the time of injury and his SCI level.

Throughout the greeting exchanges the psychic orientation to vulnerability of such serious injuries of the bodymind waxes and wanes in intensity. However, the empathic alignment with the disability habitus remains constant. Each person is aligned with their own and others' bodyminds, their SCIs, and the necessary injury they need to present to the group of disabled people who, they assume, will be able to place their greeting in the appropriate social order. In the greeting exchange, interlocutors engage in tactics associated with self-presentation (Goffman 1956), as well as the "assessment of others, and the negotiation of interpersonal relations" (Hilleweart 2016, 1). Of course, these greetings are configured by the institutional context in which they occur (Carr 2009). In contrast to the scaffolded greeting of the novice patient, the participant framework of the peer mentors allows them to prompt and build on the emotional stance associated with vulnerability. Alignment is essential, as the peer mentors establish a moral framework in which vulnerability can be taken up through comparison and alignment. As Carr noted in her analysis of institutional participant roles, greeting and form of identification becomes routinized. Enactment of disability habitus through routine greetings is an important sign of disability sociality, and the alignment among disabled interlocutors is an important thread that weaves together the fabric of the community.

For the purposes of rehabilitation, these self-identifications are key, as SCI level and severity impacts the kind of function that a person has. Someone with a C-4 injury will likely experience impairment in their ability to use the muscles in anything below their SCI level (around the neck down). Their function will be different, and they will need to learn to orient to their bodies differently than someone with a T-12 injury, who will not experience impairment in their arms and most of their core. This information is essential, as patients will need different types of support from peer mentors depending on their level of injury. For instance, a quadriplegic peer mentor can successfully model how to use their phone with impaired hands, but this type of modeling will be less important for a patient who is a paraplegic and has full use of his or her hands.

More than simply learning to identify what kinds of skills would help a patient, understanding a person’s SCI has important implications for how they fit into the community. Through identifying themselves by their SCI, they are performing a disabled identity and signifying their belonging within the social landscape. As Butler has claimed with gender (1990; 2011), through the continual amalgamation of identity performances, speakers *do* disability: disability is a reality that gains materiality through the sedimentation of such performances. Within disability sociality, SCI is a social fact that can be read and understood by those with experience in the community. For peer mentors, the ability to read the body is an important aspect of their job. In the following exchange, a peer mentor trainee (Mick) and supervisor (Kyle) take a distancing stance from paraplegics unable to perform simple tasks that they, as quadriplegics, can perform. In doing so, they implicate a contrast with themselves, quadriplegics with limited function of their hands and arms, who are seemingly more functional.

Transcript 4.4: “You’re a T12 buddy”

1	Mick	I DO know some paras that when the FIRST get injured, they’re like (.)
2		Their legs and everything is dead weight, how do you-
3		“↑Dude use your ↑arms! (.6) [(Get ↑dressed) XX”
4	Kyle	[I- I know a para that doesn’t (.) put on his shoes
5		And he’s like a T°↑12°! (.)
6		He’s like “You put on your own shoes?”
7		And I’m like “YEAH I put on my own shoes.” (.)
8		I’m like “W- you don’t?”
9		N he’s like “No (.) my wife does.”
10	Mick	Ch@
11	Kyle	Like “°You’re a T12 buddy.°” Ya know?
12		But some people think it’s im↑possible.

In this transcript, Mick and Kyle build a stance of distance and humor to distinguish between themselves and novice paraplegics who do not have the functional ability that veteran quadriplegics like Mick and Kyle. Mick incorporates reported speech into his discourse to demonstrate a distancing stance when, responding to the “paras” (paraplegics) who cannot figure out how to move their legs, he says “Dude use your arms” (line 3). He uses the ‘dude’ as a term of address that represents both social solidarity (having an SCI in common) and moral distance (a quadriplegic who has more ability and disability expertise than a supposedly less disabled paraplegic) (Kiesling 2004). Mick’s intonation heightens the irony to which he is drawing attention. Kyle builds on this distancing stance by describing a paraplegic who “doesn’t put on his shoes” (line 4). In the reported speech of his para acquaintance, Kyle builds moral disaffiliation between himself and his acquaintance through implying surprise at Kyle’s function. Another distancing stance lodges in their bodyminds: As a quadriplegic, Kyle could be less capable, but he is instead more functional than the paraplegic who cannot put his shoes on. His use of “buddy” in line 11 collapses the stances of social solidarity yet moral distance that Mick signaled earlier in the interaction.

In addition, Mick and Kyle build their social positions as disability experts. Kyle communicates a deep knowledge of the medical system in which SCIs are classified when he refers to his acquaintance as a “T12.” His use of this labeling system goes beyond simply drawing a distinction between ‘paras’ and ‘quads,’ because a T-12 injury is relatively low in the spinal cord. This means that a person with a T-12 injury should have use of most of their abdominal muscles, which are beneficial for functioning, even if someone uses a wheelchair. Kyle conveys his understanding of this system through the irony that he builds into the interaction when he says “You’re a T12 buddy. Ya know?” Kyle demonstrates expertise through such usage of insider language. Disability expertise is based on his ability to *read* disabled bodyminds. I use *read* in to emphasize the finely attuned sense of “professional vision” (C.

Goodwin 1994) that is embedded in Kyle's and Mick's knowledge of SCI: As Goodwin (1994, 606) explains:

> Discursive practices are used by members of a profession to shape events in the domains subject to their professional scrutiny. The shaping process creates the objects of knowledge that become the insignia of a profession's craft: the theories, artifacts, and bodies of expertise that distinguish it from other professions. Analysis of the methods used by members of a community to build and contest the events that structure their lifeworld contributes to the development of a practice-based theory of knowledge and action.

In the same vein as Goodwin's account of a police officer's explanation of the Rodney King beating, Kyle and Mick display a professional vision of disabled bodyminds that they have accrued through their socialization into this particular community and profession. They adopt moralized alignment or disalignment with the actions of disabled people; in doing so, they position themselves as experts in the field. This finely tuned ability to read disabled bodyminds also re-instantiates ableist ideals that circulate through rehabilitation - that disabled people should work to sustain their functionality and, if they do not, judgments about the deficiency of character are justified.

As SCI greetings and peer mentors' professional vision are integral to the disability habitus, so, too, are the frequent topics of conversation. In the next section, I analyze interactions around taboo material, such as excretion and sex, and the ways in which peer mentors frame these typically unmentionable topics as ordinary. In doing so, they begin to chip away at life-long constructions of avoidance surrounding the disabled bodymind.

Socializing ordinariness in speaking about the unspeakable

Ever since sustaining my disability thirteen years ago, I have used a colostomy bag. My large intestine has been re-routed so that it protrudes out of my skin in my abdomen and I must always have bag that adheres to skin around my intestine, to catch the solid waste my bodymind produces. One of the things that I found so alluring about the disability community following my injury was that I could participate in open and often humorous conversations about my and others' non-normative means of excretion, and other taboo bodily topics. Upon entering the field at Rancho, I was not surprised that conversations about such 'unspeakable' (Irvine 2011) topics were frequent. Disabled people at the hospital often engaged in discussions of bowel and bladder care in everyday conversation. This "descent into the ordinary" (Das 2007; Wool 2015) was a means of managing the immense changes associated with injury. Furthermore, some of the SCI Starting Out Classes were devoted to these topics, including a day on bowel care, one on bladder care, and one on sex. When peer mentors referred to themselves as "open books," it was often with these topics in mind. As such, they were seen as experts by patients in the hospital on such matters.

Openness became clear to me one day when I was shadowing David, one of the peer mentors, during his work in the SCI transition clinic. The clinic is a space in the outpatient building where, once a week, newly injured folks with SCIs had appointments with doctors to discuss the issues associated with transitioning from rehabilitation to the home. A peer mentor, usually David because he was fluent in both Spanish and English, was assigned to the clinic and given a room full of pamphlets, where doctors would send patients after their appointments. This practice allowed the peer mentor to catch folks in need of resources or support and hand out the appropriate pamphlet or simply provide advice from their perspective of disability expertise. The clinic was typically quite slow for the peer mentor. More than half the patients missed appointments, often because of difficulty with transportation. Even when they did show up, doctors would sometimes decide to forgo their recommendation that patients visit with the mentors.

During one of these slow days, David decided to move to a common waiting room outside of the clinic, where patients congregated as they waited for all kinds of appointments (not simply SCI transition clinic appointments). I sat and chatted with him for about five minutes before a middle-aged man was pushed in his wheelchair to the check-in counter, where he plopped a catheter bag full of urine. The woman working at the counter located the person to collect the urine, and the man rolled over to us to sit and wait for his appointment. He pulled his wheelchair up right next to David and asked, “are you complete?” David explained his injury to the man who grimaced sympathetically, despite David’s nonchalant demeanor. The man told David that he had an SCI at the T-9 level due to a gunshot. This was all the small talk that the patient needed before he began explaining the issues that he was having due to urinary tract infections (UTIs). He told David (and I refer only to David because, though I was sitting right beside David, I was merely an unratified overhearer in the interaction) that he kept getting UTIs. Yet, when he finally cleared up the last infection, he found that urine kept leaking into his diaper, even though he was infection free. David and the man got into a detailed and specific discussion of how many “ccs (cubic centimeters) of urine” the man was producing, what kind of catheters both of them used, their side effects of UTIs and how frequently they “cathed” (catheterized).

This conversation is an example of the ease with which disabled people, especially peer mentors, discussed topics that might make them vulnerable elsewhere, such as problems with urine, and the admission that one wears a diaper. In his research among disabled war veterans in Turkey, Açıksöz (2002a) refers to this discourse around of taboo topics as “fleshly intimacy.” As in the context that Açıksöz describes, these discourses serve to build solidarity among people with similar experiences of abjections. Even in contexts in which taboo topics are not the focus of discussion, they can be seamlessly woven in. For instance, during the peer mentor training, the leader of the course asked each trainee to list their favorite resource related to their disability. Many trainees listed grants they had received to cover expenses related such as wheelchairs or home modifications. When it was Vegeta's turn, he answered "health care." When asked to elaborate, he explained:

Transcript 4.5: Medical supplies

1	Vegeta	If it wasn't for health care, like Medi-Cal or Medicare (.) I wouldn't be here.
2		U-ah (.) they supplies me with (.) medical supplies=
3		=Catheters, (.) diapers, underpads (.) anything you need, you know?

In explaining the types of supplies that he is provided through public health care, Vegeta projects a stance of alignment with the other folks with SCIs in the room. In line 3, he makes a list of supplies that includes catheters, diapers, and underpads (likely referring to waterproof pads that he can put in bed or on surfaces on which he sits so that, if he urinates on them, clean-up is easy). This line is delivered with minimal hedging and no disfluency, suggesting that he does not need feel the need to explain his use of these objects which, in other circles, is likely something he would not talk about. Even though not everyone with a SCI relies on these medical supplies, and even though he is not referencing something that had been said earlier in the conversation, Vegeta does not seem to express shame or hesitation in uttering these otherwise 'unmentionable' topics. He relies on his interlocutors' disability expertise to contextualize this information within their social networks and knowledge of SCI. Indeed, following the utterance, the conversation simply continues with no interlocutors treating this 'unmentionable' material as a faultable. This is an example of the alignment among disabled folks at Rancho, an alignment that is integral to generating the disability habitus.

As discussed in Transcript 4.2, peer mentors and clinicians have different participant roles. These effect how and what they contribute to an interaction, including taboo topics. In the bowel Starting Out Class, the nurse who led the session typically began with explanations of the medical function of the bowel system and the impacts of SCI. For instance, the nurse would describe the way in which the signal between brain and gut could be disturbed by severed nerves in the spinal column. Such descriptions tended to highlight the unruliness of the disabled bowel system. The cold logic of science in this language (Bauman and Briggs 2003) indexed (Silverstein 1976) a kind of knowledge obtained through formal education, such as medical textbooks. Furthermore, this scientific discourse stressed the biomedical pathology of a bodymind with a SCI and implied that the able-bodymind is a standard against which deviations should be compared.

Alternatively, I observed Forest, the peer mentor most often assigned to aid in the bowel class, weekly provide an explanation of his bowel routine that highlighted his embodied experience of disability. He described his bowel program with his caretaker, who used digital stimulation (inserting a finger into the anus and moving it in a circular motion - referred to by people with disability expertise as dig. stim.) to prompt daily bowel movements. Forrest demonstrated this embodied knowledge by lifting his hand (in which he did not have complete function due to quadriplegia), to demonstrate the motion his nurse would use during this daily routine. Each time that I observed this enactment of his daily routine, he would tell the class, “My nurse and I know the bowel movement is over when we see butt snot.” His personal lexical coinage for the mucus that signifies the end of his bowel movement is an example of disability expertise derived from his experience. Furthermore, he demonstrates a rationality for his bodymind, even though it is portrayed in scientific discourse as unruly. Through this embodied language and linguistic choices, Forest provides a glimpse of his expertise, embedded in his disability habitus. The discursive construction of this knowledge often contrasts with that of institutional, scientific perspective on disability. Forest orients to his bodymind as something lived-in; this sense of embodiment is heightened by the non-scientific lexical choices, such as "butt snot," which conveys closeness, as opposed to the distancing stance imposed through scientific (often Latinate) terminology for the bodymind (Bauman and Briggs 2003; Irvine 2011).

In a sense, this language plays with the institutional power dynamics in which authority is derived through formal education (Thornborrow 2014), a 'characteristically asymmetrical' (Drew and Heritage 1992, 42) setting for conversation. Forest, who often described himself as an "open book," enacts this openness by inviting patients to align with him at the level of his lived experience. This disposition is the opposite of the objectifying stance that is produced and maintained through scientific, institutional discourse. Such discourse promotes a rational, scientific distance from taboo functions of the body. Even more, this discourse, which upholds taboo, also upholds the phenomenological distance between "normally" functioning bodyminds and those with SCI. For clinicians, objectification is necessary because the nurses are tasked with discussing topics that are potentially transgressive, and identity threating to patients. Their participant role does not allow them to make the close existential alignment with disabled patients that can be established by the peer mentors.

This was obvious in the discourse of one peer mentor, Juice, who explained to the bowel class he was not afraid to say that he had an issue for years with "anal leakage." He joked that it was not fun for his wife to say, "hey why are your chonies dirty?" This invites his ratified audience of inpatients to imagine a body with a function that might be embarrassing; however, the mentor diminishes the taboo through the open manner with which he recounts his experience. Furthermore, his use of the word ‘chonies,’ a Spanish-English blend word referring to underwear, renders his lived experience more familiar to any inpatients familiar with the term. This vernacular conveys a much warmer sense of alignment than the cold voice of science. Juice’s use of self-effacing humor, when he voices his wife, further lessens the distance between the patients and himself through the personal, intimate topic of conversation of his dirty laundry. At the same time, Juice performs standard gender relationships, as man with a wife who does his laundry for him.

In another bowel Starting Out class, Mike described the depression that he experienced transitioning from rehabilitation to his house, when he realized that he would have to “keister” his anal suppository every day. Outside of the class, I asked him what he was referring to and he explained that keistering refers to the specific act of hiding an object in one’s anus to sneak it into prison. He alluded to the link between this knowledge and his life former incarceration. I observed two different classes in which he voiced his past self, saying “Man, I’m gonna have to kesiter this thing up my ass every day.” This ironic, affect-laden vernacular invited alignment among the patients who might have similarly felt repulsed by the idea of inserting something into their anus as part of their daily routine. He made this feeling of abjection tangible while simultaneously indexing parallel consequences of two institutions: prison and the rehabilitation hospital. While rehabilitative logic has been described as *enforcing* compliance among disabled subjects (McRuer 2006; Stiker 1982), this peer mentor’s discourse *evokes* their imagination of the necessary indignities of a body that is noncompliant through its link to the incarcerated body. Using a poetic analogy, the peer mentor coaxes an audience of patients who might otherwise be “noncompliant.”

The next two exchanges demonstrate the ambivalence between the institutional voice and the peer mentors' vernacular voice, as they play out in the sexuality Starting Out Class. We have been introduced to the participants in a greeting exchange analyzed earlier. The interlocutors include Dr. Alice, a psychologist who runs the class, Bam, the new inpatient with a SCI at L-2, and peer mentors David and Mariana. Leading up to the transcribed sections of the class, the interlocutors had been discussing how SCI might affect a man's ability to have an erection and ejaculate. Dr. Alice had gone through her familiar explanation of the biology of sex, describing the path of sexual messages that travel through the spinal cord between the brain and erogenous zones, which, as she explains "is just a fancy way of saying places that are sexually exciting to touch." As with all other body functions described thus far, a SCI can interfere with that message. She ends her explanation by offering this to Bam:

> Having said that your body has been through a lot, you're on a ton of medications, you may be in pain, you may have had abdominal or back surgeries and all of those things can affect your ability to have an erection right now.

This explanation seems to stand out as a guard against any anxiety that Bam may be experiencing, if he is not able to have an erection. It also sets up the ensuing interaction below.

Transcript 4.6: Erection anxiety

1	David	I think the body's like "we've got more important things to do right now"
2	Dr. Alice	Like seriously, (.) yeah exactly [it's j-
3	Bam	[Yeah that's what I was gonna say
4		Cause, like (.) my GIRLfriend be coming sometimes,
5		Like, it's like (.) I really can't, like (.)
6		Basically, like (.) feel me going up or not, like (.)
7	Dr. Alice	So do you have sensation in your penis right now?
8	Bam	Not really that's what I'm saying, like=
9	Dr. Alice	=↑Ok, yeah. (.) So do you ever observe (.)
10		This sounds very clinical, I'm like
11		"Do you ever observe your penis becoming erect?" <in exaggerated voice>
12	David	h@@
13	Dr. Alice	But what freaks people out sometimes is, they'll be getting an erection

14 and they’re like, “I do not feel that at a:ll!”
15 Bam yeah that's what I'm saying like, XX man I can't get hard-
16 David but then again-
17 Bam I did all the extra-and I'm like, man I told you, “and (I'm not gonna go up.”)
18 David Yeah but then again, your body still does what your (.) body does?
19 So like for us, like we like- when we go to ↑sleep
20 Or like when we wake up, a lota times when we wake up we have erections
21 Like (.) we don’t even think about THAT.

In line 1, David responds to Dr. Alice’s explanation of genital functioning with SCI by voicing Bam’s body: “we’ve got more important things to do right now.” He serves as a language broker (Garcia-Sanchez 2014) who mediates between the clinician (tasked with voicing the institution) and the patient. David’s shift in footing through voicing the body is accompanied by his shift from scientific discourse to everyday language. It opens a vernacular, more casual space for Bam to explore the discussion of his inability to have an erection – a subject matter he seems to be uncomfortable talking about. Bam shows evidence of discomfort in lines 5, 6, 8, 15 and 17, as he pauses often, restarts his statement several times, and leaves his thoughts incomplete and stalled with the filler ‘like.’

Bam’s hesitation is likely associated with the face-threatening nature of discussing an inability to have an erection, particularly to his masculinity. Unlike David, who uses the pronoun “we” to refer to Bam’s entire bodymind, as in “*we’ve* got more important things to do,” Bam refers to his bodymind focusing only on one part – his penis – as in “feel *me* going up.” Throughout the interaction, David subtly shifts footing to expand Bam’s “me” to incorporate a bodymind that is more than simply a penis. He is met with alignment and reframing from David. In line 18, David picks up on Bam’s affective stance in which he recounts a conversation with his girlfriend (it emerges later in the interaction that his girlfriend is pressuring him to have sex, though he is not interested in it). Through a slight shift in footing and a disagreement (“but then again”), David reframes Bam’s seeming anxiety. He explains “your body still does what your body does." This general statement is elaborated in lines 20 and 21, as David explains that he is referring to the ability to have an erection. He aligns with Bam through using the pronoun "we." This "we" extends beyond simply 'we' as people with male genitalia, but includes 'we' as men with spinal cord injuries.

In contrast, Dr. Alice focused on the body part of the penis that is affected by Bam's SCI. In line 11, she asks about Bam's sensation and the function of his penis. She utters this line in an exaggerated voice, which draws laughter from a participant. She even calls out her utterance as a faultable in line 10 by noting that "this sounds very clinical." Again, she returns the focus to genitalia affected by SCI in lines 13 and 14, when she voices men with SCI as "not feeling *that* [erection] at all." Dr. Alice's participant role, which orients her to discuss biological sexual function, continues to make it difficult for her to appropriately address Bam's vulnerability. In the next interaction from a bit later in the class, she invites the peer mentors to contribute. Their roles are as experts on the lived experience of disability, who can explore different dimensions of common ground.

In the following exchange, the psychologist and peer mentors respond to Bam's seeming discomfort and anxiety.

Transcript 4.7: Targeted linguistic response

1	Dr. Alice	Ok. (.) d- have- (.) are you a- (.) is that sum'in you're interested in at all?
2		Sorry you'll find we're very direct
3		In terms of getting her off, is that something you're interested in at all, er?
4	Bam	Right now? No.
5	Dr. Alice	Ok. I think it's ok to tell her that.
6		I mean what do you guys think?
7	David	(.) Yeah, I mean if you're- [if you-
8	Bam	[Like I tried to tell her, but she like (.) XX
9	Mariana	[h@@@
10	David	[Well that's the thing, if you don't feel like you are ready, or you don't-
11		Or just simply don't WANT to? (.)
12		Um, I mean, you don't have to have sex if you don't want to.

13 Mariana Yeah, I mean it's [understandable
14 Bam [Yeah basically, me, like (.) I'm trying to get BEtter first.
15 Dr. Alice ↑Yeah.
16 David Yeah
17 Mariana That's what I was gonna say
18 I mean when we're all injured (.) like, you know
19 Some people it's their first concern?
20 Other people, (.) for mySELF, like for myself? (.)
21 I was just thinking (.) you know "what am I gonna do."
22 "Am I gonna be able to WORK?"
23 "What am I gonna do when I go HOME?"=
24 Bam =(Yeah)
25 Mariana "Where am I gonna live?" Um, you know
26 At the time I was living with my brother
27 My parents didn't live (.) here,
28 So I- I wasn't sure what I was gonna do
29 So it was REALLY literally the last thing on my mind
30 The last thing I wanted to do.
31 David Yeah you've got more important things to do right now.

This excerpt begins with Dr. Alice's disfluency (line 1). Her speech is full of restarts and pauses, as she struggles to figure out the best way to ask a "direct" question about sex. She, again, displays her awkwardness in addressing the inappropriate, face-threatening topic into which she is beckoned and foreshadows her question in line 3 as a faultable (line 2). To respond to Bam's expressed lack of desire and interest in sex (line 4), she invites the peer mentors into the interaction by asking, "what do you guys think?" As in the previous excerpt, the mentors adopt a stance of alignment with Bam. In lines 10-12, David justifies Bam's lack of interest in sex. Mariana responds by shifting the focus away from sex while concurrently aligning her past self with Bam's present self. In lines 21-23 and 25, she voices her past thoughts directly following her SCI. In doing so, she invites Bam's present self to identify with her. Perhaps the voicing of these thoughts allows Bam to put into language some of the thoughts that are keeping him from desiring sex in the present – a task that his disfluency suggests he might be struggling with. Indeed, Bam expresses alignment in line 24 with his latching utterance of "Yeah."

Interestingly, Mariana takes on a stance of alignment with Bam not only based on SCI; she also constructs an existential scenario regarding her *past* self with which Bam is invited to align. In doing so, she also foreshadows a future in which sex could be on the table for Bam, once he addresses his present concern of getting "better." This interaction creates a space in which Bam can imagine alternative forms of masculinity and sexuality, despite genitalia that may not function according to normative expectations that men should be able to sustain and maintain erections (Açıksöz 2015; Wool 2016).

It is possible that Bam imagines "getting better" differently than Mariana, David and Dr. Alice. I met many inpatients who imagined that they would relearn to walk and regain the function that they had before sustaining their SCIs, though a full "recovery" was unlikely for most of them. I also met peer mentors who described seeing their past selves in these patients. It was common for people to tell me that they were determined to *walk* out of the hospital. Yet, all the SCI peer mentors enrolled in the study depended on wheelchairs for daily mobility. Although it was rare, I even heard of a doctor who tried to protect patients from imagining a future for themselves in which they would not walk. For instance, one mentor told me that a doctor had specifically asked her not to visit a patient because the doctor anticipated that the patient would regain enough function to walk. He was worried that seeing a peer mentor in a wheelchair might either depress her, or not allow her to imagine her more "mobile" future.

In this interaction, Mariana or David could have dis-aligned with Bam's imagination of getting better. Instead, they adopted stances of alignment. I argue that this is because alignment is at the heart of peer mentoring. One of the main roles of peer mentoring is that newly injured patients can speak with someone who understands what it is like to sustain a SCI and rebuild a life around it. This alignment relies on disability expertise of peer mentors obtained through lived experience. This expertise is quite different from that of the non-disabled clinicians, such as Dr. Alice in the interaction. She has a great deal of knowledge *about* sexual function and SCI, but she does not know the *lived experience of* SCI. In the next section, I further explore this peer mentor-to-mentee alignment by examining the temporal stances of mentors.

Orienting to an ordinary future

In her explanation of crip temporality, Kafer argues that the social imagination of a curative future that eliminates disability is inherently ableist (Kafer 2013; see also Clare 2017). Medical anthropologists have also remarked on the eugenic undertones of efforts to rid the future of disability (e.g. Lock 2007; Rapp 1988; Rapp and Ginsburg 2001; Thomas 2016). As the analysis in this chapter has demonstrated thus far, peer mentors offer an alternative to this curative future by serving as an embodiment of SCI patients' lived futures. Furthermore, Kafer critiques the tendency to think about people with acquired disabilities as having two selves - one existing before injury, and one existing after. She claims that

> we [crips] are expected to take up nostalgic positions toward our former selves, mourning what we have lost and what can now never be. Thus the lost pasts… rely on an assumption that all disabled people long for a lost whole, pre-illness, pre-disability body (Kafer 2013, 43).

In line with Kafer's reading of disability narratives, Rancho is rife with people taking temporal orientations towards their past, able-bodyminded selves, their present disabled selves, and future self. I suggest that this denouncement of the curative future is complicated by the lived experience of disabled folks, especially those in rehabilitation. For many people, the desire is that this self be free of impairment (Mattingly 1998). I argue that this dual-self-conception is an essential aspect of entrance into the disability community. Peer mentors evoke temporal stances in which their (disabled) futures are *ordinary* (Sacks 1984). They do this through exercising disability expertise that they have learned from embodied experience. As Kyle explains: “I’m going into somebody’s room that’s life will never be the same.” This statement richly conveys the heaviness of working with folks in the beginning of coping with a life-changing impairment. Furthermore, it positions the moment of sustaining a SCI as a massive temporal shift. I argue that orienting towards injury as a rupture in a person’s life trajectory does not necessarily impose “compulsory able-bodiedness” (Kafer 2013), if that orientation is accompanied by an alignment to a future life with a disability.

During a peer mentor training session, supervisors, Jim and Robert, espoused the virtues of mentoring by explaining:

Transcript 4.8: “They can’t tell you how WE feel”

1	Jim	Patient’s laying in bed, and XX
2		And (.) doctor comes in, nurse come in, nurse comes in, therapist comes in,
3		All these people who are (.) walkin ↑around,
4		And (.) they’re ↑fine, and (.) they’re checkin on you,
5		And (.) at SOME point, it just becomes a blanket of (.) too many people
6		And, all of a SUDDEN, somebody else (.) you know, ro:lls in. (.)
7		Or walks in on a cane. (.) Or something like that
8		And they (1.2) underSTAND. (.)
9		And you guys get to be that person.
10		It’s really- (.) It’s a really cool thing.
11	Robert	We KNOW exACTLY how they’re feeling.
12		I mean, (.) I don’t care (.) how much (.) schooling you have,
13		A doctor (.) They-they can’t (.) They can’t tell you how (.) WE feel.

In this transcript, Jim contrasts the impact of someone in rehabilitation interacting with people who are “walking around” (line 3), a phrase which he emphasizes with a pause and a shift in pitch, with an interaction with a disabled person. In line 4, when he uses the second person pronoun ‘you’ to refer to the patient, he builds a stance of alignment with all of the trainees’ past selves in rehabilitation. It is a seamless shift from the unmarked rehabilitation patient to the plural “you,” as in ‘all of you who have experienced sustaining an injury and laying in a rehabilitation hospital bed.’ As he continues his utterance, his pauses help heighten the dramatic turning point to which he builds - the point at which the patient interacts with a (visibly) disabled person (line 6 and 7), which he implies is a peer mentor. Jim marks this radical, existential change in a disabled person’s life narrative through the adverb “all of a SUDDEN”. This marker heightens the abrupt psychological change of state from “at SOME point, it just becomes a blanket of (.) too many people.” Jim further heightens this turning point drama through lengthening the vowel in “rolls” in line 6, and increasing his volume, as in “they (1.2) underSTAND” in line 8. He closes his heroic narrative in line 9 by motivationally directing the trainees “you guys get to be that person.” Jim projects them as future protagonists in their own versions of this template narrative. The contours of alignment that he constructs make a dramatic shift, from aligning the trainees with patients, to aligning to the trainees with “that person” who forms a meaningful connection (yet another alignment) with rehabilitating patients. To build on the interaction, Robert provides metacommentary on disability expertise when he contrasts doctors’ schooling with the embodied experience of disability. He expands the alignment to everyone in the room when he says “They can’t tell you how WE feel” (line 13).

Throughout the interaction, Jim and Robert build a stance of expertise through the possibility for affective alignment among disabled people who “understand.” This affective alignment relies on a complex web of temporal orientation for those possessing disability expertise. The alignment depends on disabled folks with lived experience orienting to their past rehabilitating selves, to other disabled people working their way through rehabilitation, and to a future ordinary self. This autobiographical consciousness allows mentees to align themselves with peer mentors, as living embodiments of their future. The mentors with whom I spoke also often orient to their past selves and express a sense of growth that has come as a result of their disabilities. Their disabilities are described as catalysts for moral improvement. For instance, Mike, the formerly incarcerated peer mentor, often told me he used to be a “mean guy,” but his SCI changed him. In the sexuality class, David would frequently tell inpatients that his SCI made him a “better lover” because he learned to care more about his partner and developed an interest in the process of sex when he lost some sexual function. Another peer mentor, Juice, told nearly all the patients he met that his SCI forced him to get out of a life of drugs and partying.

In the context of SCI rehabilitation, Mattingly (1998) proposes the concept of therapeutic emplotment to explain how occupational therapists structure experience in clinical settings to resemble narrative. In doing so, they transform ordinary events, like playing checkers, into a climactic series of temporally organized events. Therapeutic emplotment connects mini events to larger rehabilitation events. In the example of the checkers game that an occupational therapist coaxes two quadriplegics into playing, Mattingly writes that therapeutic emplotment “concerns the way playing this particular game, with these particular actors, connects to a more sweeping narrative vista, encompassing a past before disability and a future which is quite possibly too terrifying to contemplate” (1998, 65). Mattingly demonstrates that, within the institutional space of rehabilitation, clinicians place disability in narratives that make a potentially terrifying life palatable. In a similar vein, Jim and Robert use a master narrative to emplot the action of meeting and aligning with disabled people amidst rehabilitation. This narrative has the rhetorical and socializing effect of heightening the emotion associated with the mission of peer mentoring and its underlying moral value.

These examples of temporal orientation provide an interesting counterexample to Kafer’s claim that a dual-self model of injury upholds a curative future model. Rather, these observations suggest that disabled folks align with each other in order to allow patients to imagine themselves as living an ordinary life, despite their disability. Peer mentors make this alignment possible, even as SCI patients cope with their immense life transformation and perhaps even mourn the death of a past self (Mattingly 1998). One peer mentor, who lamented that it took him years to figure out some of the disability-specific knowledge he acquired after becoming a quadriplegic, made a direct comparison to the value of sharing knowledge and economic value:

Transcript 4.9: "Save em years of time"

1 Papi No. Yeah, peer mentoring is grea:t because the sooner you could (.) tap into-
2 Er- er meet someone that just got injured? (.)
3 And express (.) an-and be (.)
4 I don't know if an example? or just a person thats got past their injury?
5 And learned all these things throughout the YEARS,
6 Now you're bestowing all that wisdom and knowledge onto them
7 So early in their injury?
8 That'll save em years of (.6) of time
9 Them tryin to figure it out by themselves,
10 Where you could get em up to speed?
11 Of all those years? (.7)
12 25- (.) 24 years of you bein injured?
13 Now you could bestow knowledge upon this person, (.)
14 one year POST (.) their injury. (.)
15 Is (.6) is treMENDOUS. It's invaluable

In this excerpt from an interview, Papi implies a moral comparison to a past self, one who did not reap the benefits of peer mentoring, with the imagined recipient of peer mentoring. This backshadowing (Bernsteing 1994) is especially clear in line 12, when he says "25- 24 year of you bein injured." This statement uses the impersonal second person pronoun, though he specifies twenty-four years, which is the amount of time he personally has lived with a disability. Papi's statement is at once a generalized template and a personal story. He transforms disability expertise into a form of life capital, worth more than monetary capital ("It's invaluable," line 15), a concept which is explored in greater detail in the next chapter. Peer socialization is a spring into which someone can “tap” (line 1). Multiple laminations of the self (McIntosh 2009) structure the larger context of disability community and sociality. While Mattingly’s research focused on the ways clinicians allow patients to imagine their future, the present analysis probes how disabled people align with and nurture each other. Patients to look at peer mentors and see themselves in the future.

Conclusion

I have argued that peer mentors are socialized into their role as mediators between the institutional, scientific voice, and the daily vernacular voice of the patients who inhabit Rancho’s halls. Furthermore, mentors envision their work as socializing patients into a moral and pragmatic disposition (disability expertise) to the disabled bodymind. This disposition is apprenticed (Lave and Wenger 1991) through presentations of self (greetings), a willingness and ability to talk about taboo topics, the ability to map the mentor’s autobiographical past on to a novice‘s present and future disabled bodymind, and the ability to cast these experiential transformations of the disabled bodymind and practices as an *ordinary* lifeworld.

The discourses of the rehabilitative institution weave a moral thread of biomedical erasure of disability (McRuer 2006; Stiker 1999). The psychologist’s well-intentioned yet objectifying, scientific logic, according to which spinal cord injured bodyminds are rendered pathological, may sound like a textbook, far distant from the lived experiences of the newly disabled and old-timers alike. The perspective of the newly arrived at Rancho resembles Alfred Schutz’s experiential of the ‘stranger’ (1944: 506):

> [T]he cultural pattern of the approached group is to the stranger not a shelter but a field of adventure, not a matter of course but a questionable topic of investigation . . . a problematic situation itself and one hard to master.

Peer mentors work like needles to weave fibers into a different logic, according to which disability is commonplace and common knowledge. Or, perhaps, peers are seam rippers, undoing taboos of “unruly” disabled bodies and their underlying ideologies. I suggest that, when the peer mentors refer to themselves as ‘open books,’ they unleash the potential of their vernacular to open horizons of consciousness, of other possible embodied subjectivities (Throop 2003). This phrasing, intended to invite newly injured patients to learn about living with disability, suggests that it is the *peer mentors*, rather than the patients, who are being “read.” In a sense, the peer mentors are training newly disabled folks to “read” them by socializing the untrained eyes to see and orient to a new life-world.

This chapter has expanded Hartblay’s notion of *disability expertise* by attending to the way this knowledge is situated both in medialized and vernacular perspectives. Attention to disability expertise serves as a reminder that, despite navigating environments often designed to exclude them, disabled people create rich social worlds. The notion of disability expertise has potential to transform the field of rehabilitation, if hospitals solidify their commitment to incorporating the wisdom of disabled people into the warp and weft of their knowledge tapestry. Peer mentorship provides an alternative realization of disability that redesigns rehabilitation as informal, vernacular-mediated learning among equals in life experiences. I wonder what rehabilitation would look like if it took seriously the battle cry, “nothing about us without us.”

CHAPTER FIVE - “I have purpose with that:” Complicit agency, value, and disability

Introduction: Protest, collective action and reassigning value

On October 29, 2002 The LA County Board of Supervisors voted 4-1 to approve a measure to shut down Rancho Los Amigos Rehabilitation Hospital on June 30, 2003 (California Healthline 2002). The proposed shut down was an effort to save money, $58.6 million to be exact, on apparently “unnecessary” (Los Angeles County Board of Supervisors Meeting, May 14, 2003) medical expenses (Richardson 2002). The decision was of immense concern to patients of the hospital, employees and disability activists. While employees feared losing their jobs, folks with disabilities who depended on care at Rancho feared their inability to access necessary medical treatment, as well as the potential that they might be stripped of independence and forced into skilled nursing facilities, or nursing homes.

Necropolitics is “the ultimate expression of sovereignty [that] resides… in the power and the capacity to dictate who may live and who must die” (Mbembe 2003, 11); the Board of Supervisors’ decision to shut down Rancho was an example of necropolitics. The decision would have forced poor, disabled people of color out of their public rehabilitation institution and into nursing homes; in doing so, it would have been forcing them to die a ‘slow death’ (Berlant 2007; Puar 2017), as most medical facilities lack the expertise to treat common conditions seen at Rancho, like SCI, post-polio, and ventilator dependence. This decision was presumably justifiable by the Board of Supervisors because of the ease with which the lives of Rancho’s population were (and continues) to be seen less valuable. Rancho provided the medically necessary care to support the patients’ biological lives, or *zoē* (Agamben 1998, 9). While a nursing home would have continued the patients’ bare lives, though likely not as long as they would have survived with the support of Rancho, it is likely that moving people from their communities to nursing homes would have cut off that aspect of their lives that exists as social citizenship, or *bios* (Agamben 1998, 9). Through first cutting off *bios* and eventually shortening *zoē,* this decision was positioned on a continuum of harm done to disabled people. The continuum ranges from lack of access to medical care for disabled and ill people (which is more likely to happen to poor people of color) to the justifiable mutilation (thus disablement) of brown and black bodies in settler colonial spaces (Puar 2015; 2017). The vote to end support for 'unnecessary' services demonstrated the ways that class, ethnicity and ability status influence the value of lives and the right, or lack thereof, to thrive (Erevelles 2011; Erevelles and Minear 2010; Ralph 2014).

During this historical moment in which passivity on the part of patients and employees would have resulted in the closure of the hospital, the interested parties banded together to forestall and ultimately upend the decision of the LA County Board of Supervisors. Employees and people with disabilities who received services at Rancho began to organize and collectively act. The union representing LA County health care workers held a protest at the hospital on November 13, 2002 (see Figure 5.1). In the same week, health care workers and patients organized letter-writing campaigns teleconferences, and online petitions. Before the proposed shut down, some of the patients staged a forty-five-day tent-city protest at the hospital, camping out on the grounds to draw attention to the dire situations they would face without access to Rancho. The visible bodies of the disabled protestors became "spectacles" for declaring grievances (Açıksöz 2020b). Interested parties aired their concerns with the LA County Board of Supervisors to no avail. When more forcible action was called for, groups began filing lawsuits. By March 2003, two lawsuits had been filed against LA County to block the shutdown of the hospital (Fox 2003; Richardson 2002). One of these lawsuits was filed by several patients, including one of the consultants in this study, Ed, on behalf of all Rancho patients. The lawsuit argued from that, according to the Americans with Disability Act (ADA) Rancho needed to remain open because no other hospital would be able to accommodate the disability-specific needs that the patients had. A judge ruled in favor of disabled patients who sued to keep Rancho open, arguing that there would be no place for disabled people without insurance or those with public insurance to go, if the hospital closed. The county system was the only place that would see patients with such limited resources, and Rancho was the only hospital that could accommodate disabled folks who required specialized care.

Figure 5.1: Patients, community members and disability activists protest Rancho's proposed shutdown by the L.A. County Board of Supervisors. The image depicts the front line of a group of demonstrators (both using wheelchairs and standing), many holding handmade signs. In the forefront of the image, a woman using a wheelchair holds a sign along with a man who is standing that reads "KEEP RANCHO OPEN" surrounded by handprints filled with different colors. Image credit: New Mobility Magazine.

This successful political action - agency kept the hospital from shutting down. In explaining that Rancho provided specialized care that patients could not receive at other institutions, those who filed the lawsuit were able to re-frame for legal experts, for the public, and for themselves the value of Rancho. They argued that the ADA demanded that, as disabled people they deserved specialized and appropriate care; Rancho was a key to providing such care.

But what exactly did preservation of the hospital protect in the lives of disabled people in whose name the suit was filed? In one sense, the political action rallied against absolute passivity for disabled people. Had the hospital been closed, many of the poorest and most severely disabled patients would have likely been sent to nursing homes (a generally undesirable setting for many due to a loss of autonomy). Or, they would have died, because they could not receive or afford specialty care. Although this political action protected agency in the form of patients' self-determination, a more complex and ambiguous form of agency is evident among the disabled folks at Rancho today. This chapter depicts the contours of this agency, as gleaned through interviews.

Value and complicit agency

Previous chapters considered the ways in which history, institutions, disability community and social relationships and the disability habitus influence one another. Rancho community members demonstrated that they creatively appropriated dispositions and practices, which were continuously revised through how they engaged with the social and physical world in the course of navigating Rancho's thick sociality. In this chapter, I take a closer look at the way the larger social and political context affects the disability habitus. In addition, I examine the ways in which individuals think, feel, and act through their disability habitus to transform the world around them. In so doing, this chapter entertains questions of agency and disability in collective political action, as in the Rancho's patient protest in the early 2000's. Other times, agency is exercised in people's daily routines and their choices to act given their (often limiting) social context. Through analysis of the language used in interviews, this chapter examines the way people navigate legal and public discourses that impose concrete constraints, like American disability policy. It also addresses ideological constraints, especially the psychological impact of existing in a neoliberal milieu in which disabled (read unproductive) bodyminds are devalued (Clare 2017; Fritsch 2015 Mitchell and Snyder 2013; 2015).

Figure 5.2 is a depiction of the areas covered in this chapter. The image shows the dynamic relation between social context, institutions, disability community and disability habitus - four interlocking levels of Rancho's thick sociality. I examine the way the social context and institutional structures impact disability community and habitus and, in return, the way disability community and habitus feed back into these external structures and shift or reify them. This chapter considers the interplay between social, political and economic structures that configure the degree of freedom of the disability habitus and how disabled persons navigate those structures.

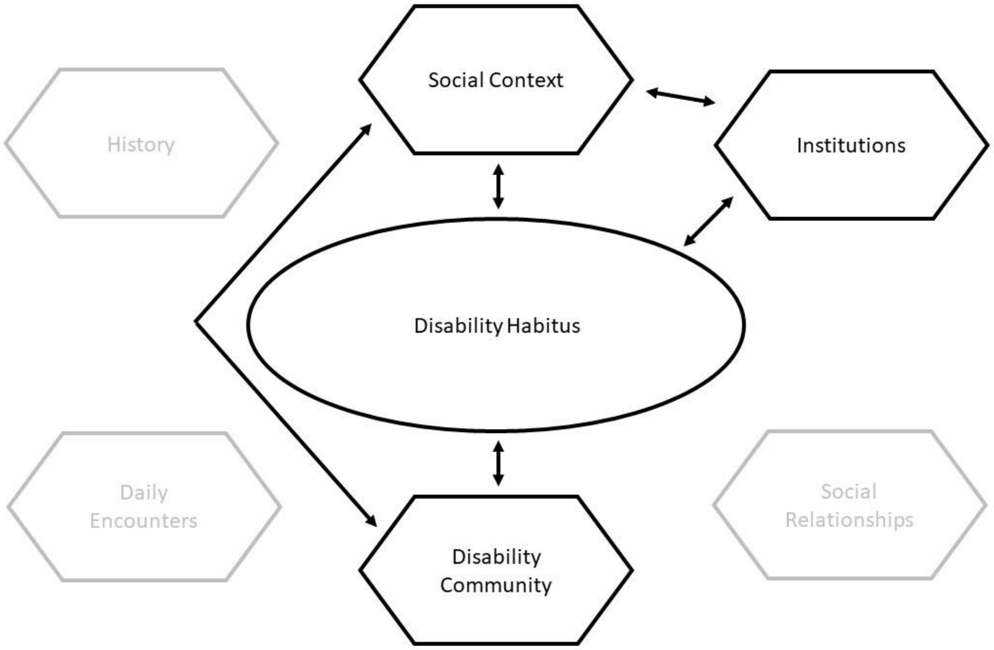

Figure 5.2: Contours of complicit agency. The image depicts the interacting facets of disability habitus with which this chapter deals: disability community; institutions; and social context.

In general, agency is "the socioculturally mediated capacity to act" (Ahearn 2001, 112; see also Bourdieu 1993; Duranti 2004; Giddens 1979; Taylor 1985)," a definition which builds on Gidden’s description of agency as a flow of causal interventions in the world (Giddens 1979). These wide-reaching definitions center agency on an ability to ‘act’ *in the world*. They attend to the influence, including the constraints and structural limitations of the world. Ahearn emphasizes the importance of defining agency specifically in the contexts within which scholars work. In the context of this fieldwork, I understand agency as a process of navigating the sometimes oppressive and ableist social structures of rehabilitation with the goal of framing one’s life as meaningful. Building on the literature of linguistic anthropology and performativity (e.g. Austin 1962; Butler 1997; Goffman 1956; 1974), which approaches language as a form of action, this chapter locates agency in language, social relationships, and power dynamics.

I follow Ahearn’s caution against conceptualizing agency too simplistically. First, I do not conceptualize of agency as free will. To do so, would be to assume that that agency is exercised by an independent self, a (neoliberal) notion I have worked to push against in this dissertation through my emphasis on community. Disability anthropology literature continually reminds us that people, especially disabled folks, are interdependent and construct meaning within their communities (e.g. Davis and Boellstorff 2016; Nakamura 2013), cultures (e.g. Hartblay 2017; Kasnitz and Shuttleworth 2001), and social structures (e.g. Açıksöz 2012; 2019; Kohrman 1999; 2003; 2005; Nakamura 2006; Phillips 2010). Scholars of interaction have also demonstrated that agency is collaborative and co-constructed (Al Zidjaly 2009; Goodwin 2004; Tannen 1994). This is important to remember in relation to disabled people, who are typically positioned ideologically as non-agentive. Second, I strive to avoid approaching agency as merely resistance, an overly romantic view of power dynamics (Abu-Lughod 1990; Ortner 1995).

The agency with which this chapter is concerned incorporates both resistance and complicity. The disabled people who portray themselves as agentive do not often resist the ableist structures of rehabilitation with oppressive ideologies about the value of able-bodyminds. Indeed, it is likely that this lack of resistance would be an object of critique by many disability studies scholars. Nonetheless, complicity can be agentive. I build on Ahearn's suggestion to describe a nuanced and contextually specific "complicit agency" (Ahearn 2001, 130). Through complicit agency, which I locate in language, interlocutors navigate neoliberal and ableist structures, not with resistance, but with a sense of calculation, in order frame their lives as moral and meaningful. Neoliberal discourse is rife with a sense of individualism and agency in which the pursuit of 'self-improvement' is a moral imperative (Cameron 2005; Inoue 2007; McElhinny 2012; Zimman 2019). Rancho community members adopted this inherently ableist discursive framing in order to make the best of the limited structures into which they were embedded.

Building on the theory of disability habitus that this dissertation has explored, I examine how the disability habitus into which Rancho participants are socialized constrains their agency in navigating social structures. At the same time, individuals navigating constraints exploit possibilities for resistance and transformation, either on their own or, more usually, in concert with others. Taking inspiration from Ortner, who approaches agency as the navigation of a social structure that is never total, (Ortner 1989), I focus on the loose institutional structures at Rancho through which disabled folks exercise agency.

In disability studies, impairment has been described as a source of value for the medical industrial complex, which profits from medical interventions (Clare 2017; Mitchell and Snyder 2010; 2013; 2015). Açıksöz (2020b) has described the debt incurred by disabled war veterans who must purchaser prostheses they cannot afford, and the debt they feel is owed to them by the Turkish state for their corporeal sacrifice to the nation. I suggest that value (Friedner 2015) provides a useful theoretical lens with which to understand the way people construct meaning in their lives. Friedner approaches value from the Marxist lens of value extraction (Marx 1887). She argues that value is extracted from deaf and disabled workers in India under the regime of neoliberalism as corporations profit from hiring “diverse” workers in the age of social responsibility initiatives. Financial value is attached to the neoliberal ideal of *inclusion*. This value, both moral and economic, sometimes benefits and sometimes fails to benefit the deaf and disabled people from whom value is extracted. I follow Friedner in approaching value as an economic and moral quality steeped in neoliberal ideology. I argue that the disabled folks’ notions of value are informed by the neoliberal milieu of rehabilitation, but also by the constraining structures of national disability policy to which they are subject.

It is important to consider value, both in the way people perceive their lives, and in the way they frame their choices in light of structural inequality. Interlocutors typically dealt with constraints related to their lack of access to social and economic resources and their status as mostly ethnic minorities and disabled folks. Therefore, I extend both the theories of agency and value; I define agency as a means of reassigning value in a given social context, inclusive of any constraints that context might impose.

Research on disability has come under recent critique for failing to recognize the global inequality (largely a result of Western and Northern imperialism) that has created unequal amounts of disability among poor communities of color (Chen 2012; Erevelles 2011; Kafer 2013), and those under the political influence of American and Western European imperial projects (Grech and Soldatic 2014; Meekosha 2011; Puar 2017). This theoretical approach to disability (Puar 2017), is in many ways, an extension of necropolitics (Mbembe 2003) and draws attention to the observation that not all disabled people are treated equally. The inequality that disabled people face is likely to intersect with other identity categories, such as those based on ethnicity and class (Bell 2017; Erevelles 2011; Erevelles and Minear 2010; Ralph 2014). Analysis of agency in this chapter explains how people can exercise agency, however limited it might appear from the outside, to navigate the ableism, racism, and classism that permeate their worlds.

Methodologically, I rely on the analytic tools of linguistic and cultural anthropology to shed light on interlocutors' agency in their everyday lives. I examine the content and form of language from person-centered, semi-structured interviews (see Chapter 1 for information on methods) to discover how interlocutors reassign value and meaning in their lives. I see their talk as a linguistic means of stringing events together in a way that emphasizes their agency. In some cases, agency is attributed grammatically through subject, agent, and object roles (see Duranti 1994; Duranti and Ochs 1990). Additionally, speakers construct themselves as morally agentive, despite the many constraints on their ability to act (see Mattingly 1998; 2010; 2014a; Rymes 1995). These moral positions are continually established through shifts in stance (Goffman 1981; McIntosh 2009), especially through voicing (Hill 1995; Tannen 1989; Voloshinov 1973). As I will demonstrate, through shifts in stance (also referred to as footing), speakers laminate (Hill 1995; McIntosh 2009) multiple affordances and constraints into their constructed sense of agency.

Concrete constraints and complicit agency

This chapter explores productivity, inaction and value among my research participants, mostly disabled people who work part time or not at all in order to care for their bodily health, and to avoid jeopardizing the economic benefits they receive. I ask: what is productivity and how does the lived experience of disability impact one's notion of productivity? Rancho is a fascinating place to theoretically engage with agency, productivity and political action and the inverse - complicity, passivity, and inaction. I argue that the results of political action in 2002 and 2003 succeeded in preserving a complicit agency; in Rancho's thick sociality, complicity within the social, political and institutional constraints is one means through which disabled people exercise their agency. Rancho describes itself as treating an "under-served population" (Rancho Los Amigos Rehabilitation Center, n.d.). The hospital's SCI population is largely composed of people identifying as members of ethnic minority groups (over 80%), and a majority of patients are "economically disadvantaged" (Rancho Los Amigos Rehabilitation Center, n.d.). These measures of marginalization were even higher among persons interviewed during fieldwork. Of the twenty-five people I interviewed, only five identified as white, and all but two people relied on governmental economic assistance because their impairment limited their ability to work. In this section, I explore the ambiguous relationships between agency and constraints associated with this monetary assistance in the form of Social Security Income (SSI), Social Security Disability Insurance (SSDI) and the related public health insurance programs, Medi-Cal and Medicare.

These welfare programs fall under the purview of the Social Security Administration (SSA), which determines eligibility for these types of assistance. SSI is available to disabled adults and children with limited economic resources (Social Security, n.d.). It provides a very modest monthly income[1] (around $900 for most interlocutors). Additionally, anyone who is eligible for SSI is automatically eligible for Medi-Cal[2], a low-cost health insurance subsidized by

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[1] The SSA has a specific algorithm for determining how much SSI someone can earn. It depends on the cost of living in the person's place of residence and how much access the recipient has to other economic assistance.

[2] Medi-Cal is California's Medicaid healthcare program.

federal and state taxes. SSDI provides monthly income to people who became disabled after working and, thus, paid into the federal disability insurance plan through their taxes. People eligible for SSDI[3] are generally eligible for Medicare, the low-cost coverage designed for retirees and disabled folks who can no longer work. I found that most of the people at Rancho had a deep knowledge of these SSA programs, because their livelihood and wellbeing depended on the monthly income and health insurance. They had to have an extensive knowledge of these programs, because the SSA imposes strict and frequently monitored restrictions on how much recipients can earn monthly and how much they can own in assets before they lose their SSI or SSDI and, often, the associated health coverage.[4]

The SSA exists as a safety net for those considered ‘unproductive in neoliberal and capitalist frameworks. These frameworks assume that individual freedom lies in people’s ability to make money, while impairment that inhibits ability to work renders a bodymind unproductive (Fritsch 2015; Mitchell and Snyder 2015; Stone 1985). In the United States, disabled people are far less likely than non-disabled people to engage in wage labor. In 2018, 19.1% of disabled people were employed, compared to 65.9% of people without disabilities (United States Department of Labor 2019). While non-working can be seen as leading an unproductive life, disability is generally viewed as a morally appropriate excuse for not working, though that may not ease the “non-working guilt” that disabled people tend to harbor (Taylor 2004). Taylor describes the ambivalence in many disabled people’s relationship to employment because social

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[3] The algorithm for determining how much income a person receives in the form of SSDI depends on how much they had earned before sustaining their disability, as well as their financial need.

[4] For instance, an SSI recipient becomes ineligible for their benefits if they earn more than $1,100 per month or have over $2,000 in a bank account.

value and social capital often depend on a person’s work. The value of working is so strong that it is legal in most states to pay people with disabilities sub-minimum wages in segregated places of employment called sheltered workshops (Gill 2005; National Conference of State Legislatures 2019). In these environments, disabled employees engage in menial tasks, such as stuffing envelopes, for sometimes less than $1 per hour (Autistic Self Advocacy Network, n.d.). The value of working in itself is promoted in these workshops, where the self-sufficiency of disabled employees and their wages are secondary to the simple activity of labor. Sheltered workshops supposedly teach social skills, even though they do not provide a living wage. Such ideologies about the value of labor permeate the social world of disabled people who need to make decisions about working.

In addition to having an underlying knowledge of the work ethic, many recipients of SSI or SSDI must also deal with the physical difficulty of laboring with an impaired bodymind. One interlocutor, Ed, explained this predicament well. One of the three people listed on the lawsuit that kept Rancho open 2003, Ed is a soft spoken, sixty-year-old quadriplegic with kind eyes and deep wrinkles in his face; a “black guy,” in his own words, who grew up in Watts, a city in Los Angeles. I most frequently saw Ed during his near-daily morning routine working out at the hospital’s Wellness Center on the hand crank, his hands strapped to the crank with special Velcro gloves. He liked to work out early in the mornings so that he could complete his exercise before people showed up at the gym. So many people on the hospital campus knew and adored Ed that their incessant attempts at conversation would prevent him from focusing on his workout. He was also a regular visitor to the community garden and friendly with the woman who volunteered to run it (see Figure 5.3).

Figure 5.3: Picture of Ed in the garden holding a bunch of kale, grown in the community recreational therapy garden. As a beloved figure at Rancho, he was given kale from which his caretaker would make a salad later that day. Photo by author.

After sustaining a spinal cord injury at the level of C4-C5 in 1979, paralyzing the lower half of his body and significantly reducing the function of his arms and hands, Ed rehabilitated for nearly a year at Rancho. He decided that he wanted to become a teacher, so he completed his teaching degree and went to work full time. However, he did not last for more than two years, because the work took a toll on him:[5]

> It's- it- It took a lota- a lot out of me. And then, I- I wasn't having (.) opportunities to de-stress physically. And I broke down with a pressure area. (.) And so I'm hospitalized for seven weeks? (.) Sh- and you still got bills right?… So at that point I just said, °ok° (.) I- I can't continue to work.

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[5] Rather than using line-by-line transcription for this chapter, I am using transcriptions of utterances as block quotes. This format allows me to take a wider focus on language than the detailed, conversation analytic style that I adopted in previous chapters.

In this chunk of talk, Ed expresses several different stances. Through his narration, he expresses the affective stance of his past self. Intense emotion is most obvious in the prosody of his utterance, “And so I’m hospitalized for seven weeks?” By ending a declarative statement with rising intonation, he draws me to focus to the emotional implications of what he is telling me. Being hospitalized for seven weeks was difficult. The hardship is made even more obvious with the pause and the expressive “Sh,” that followed. “Sh,” is expresses empathy from his present self to his past self. He further draws me, his ratified addressee, into this affective space, with the generalized second person pronoun, when he says, “and you still got bills right?” By asking this question, he encourages an emotional identification between me, his present self and the difficult situation of his past self. After expressing the affectively and economically difficult situation, he explains the resolution that he reached: he could not continue to work. Through building up this resolution with his affective stance taking, Ed displays the complicit agency that he exercised through his decision making.

Furthermore, Ed’s ability to work was also stymied by the state and federal resources that provided him aid. For instance, his bank account was monitored by the housing authority that oversaw his subsidized rent. He had to furnish explanations for any deposits into the account, for instance the $200 that his sister transferred to him when his balance dropped below $0. Additionally, the SSA monitored his work record and looked for any income over roughly $1000 per month, which would put him at risk of losing the SSI benefits (just over $900 per month) that he relied on to pay his bills. Thus, Ed explained, he was “held prisoner by social security.” Even when given the opportunity to work part time and earn under the limit, Ed decided to forgo this income because of the “stress” of reporting to the SSA. Ed’s metaphor of social security as a carceral system emphasizes far-reaching social system of disenfranchisement. He exercised complicit agency by making the choice not to work and staying within the confines of SSA restrictions, however, he still felt penned in by this decision.

The peer mentors, some of whom are paid for their work, provide a wealth of knowledge about navigating these systems that conceptualize of disabled people as non-agentive. For many peer mentors, while the wage is valuable, working and not losing benefits is a fine juggling act. One peer mentor supervisor told me that he had just received a raise and, therefore, had to cut back his hours. Other supervisors (many of whom felt especially responsible for their jobs because of their management positions) explained that they would work as much as they needed to in a month to complete their tasks, but they submitted a time-card only for the hours that did not put them over their SSI or SSDI limit. One supervisor, Quadupp said, "At the end of month when I put [in] my time-card, when I reached that max… line, which is almost every month, then those other hours just drop off." Quadupp's familiarity with the process of not maxing out his earnings is an ever-present theme in interlocutor's disability expertise (Hartblay 2019; see also Chapter 4). It was so common that it appears to be a nearly automatic behavior instilled in the disability habitus. When I spoke with interlocutors about how they made decisions about working and not jeopardizing their benefits, I found that most people had a very specific knowledge of exactly how much money was allowable. For instance, Mariana explained:

> I get SSDI, and then I also have Medi-Cal and Medicare… So for me, because this is pretty much the only employment I DO have, I make the choice to not make more than the amount that they let you make, which is I think is a thousand… So for me, I make the choice to just not go beyond that so I don't lose my benefits. And for now, (.) it works. Fortunately, I live at home, so I don't have to worry about, like, you know, $1,200 rent H@.

Mariana takes up several stances related to the regulations of disability policy to which she is beholden. She describes herself as compliant within the system by explaining twice that she does not make more than her limit. She qualifies this compliance by saying, “So for me, I make the choice,” a qualification that figures her not simply as compliant, but also as agentive. Her emphasis on *choice* also distances her from others, who face more strife within in this system. Mariana refers to the SSA with the pronoun “they,” as in “the amount that *they* let you make.” This generalized, third person pronoun refers to a complicated, anonymous system of bureaucracy, law, and the 60,000 employees that are part of the system which determines how much money she can make. Furthermore, Mariana explains herself as stable in the present moment (“for now, it works”). Her evaluation of her situation is not affectively enthusiastic. Her word choice of “it works” conveys an image of surviving, though not thriving. Also, with her use of “for now,” she contrasts her current self with an imagined future self, the self that might move away from home and have to pay the $1,200 rent she imagines herself paying. Her laughter at the end draws attention to the irony of the situation, that her rent will likely cost more than what she can make with her benefits if she moves out. This distancing stance highlights the irony of the SSA regulations; it alludes to the catch-22 in which Ed referred to himself as a “prisoner.” Her language subtly displays the ambiguity she lives within: she is getting by alright for now, though she is in a precarious situation that requires her vigilance to make sure that: 1) she does not go over her maximum earnings, 2) while still living within her means in the Los Angeles area, 3) where cost of living is among the highest in the country (Stiles 2019). Like the families in Mattingly’s *Moral Laboratories* (2014a), Mariana demonstrates her future orientation, even though that future is uncertain.

The passages above show the complicit agency with which disabled people navigate constraints, such as the monetary constraints imposed by the SSA. Ed, Quadupp, and Mariana have access to monetary resources that they come to depend on through SSI and SSDI. These allow them the ability to survive or, as Mariana explains, make it “work.” Yet, they are ever attentive to adhering to the guidelines embedded in a structure in which benefits that accompany the status of ‘disabled’ force recipients to continually prove their non-productivity to the state. Despite the constraints, many people find clever ways to exercise some agency within these systems. For instance, Amadeus explained how he works as a contractor to earn the maximum amount of wages. This was something he only learned through being penalized by the state earlier in his life:

> I decided to be an independent contractor, ‘cause that- it just works out the best. You know, when you- when you have your own business, there's a lot of write-offs that you get that that doesn't count towards how much money you actually make. So, I know when- when I was when I was a W2 employee, for one of the radio stations, it kind of put me in a situation where I almost lost all my benefits because of making too much money. So once you are working, if the, if you’re below the max then you're OK. I think you make $1,000… So I try to always make sure… I'm under that. Yeah. Even- even if I have to turn away work because, just of the rising costs of medical- medicine, medical supplies…

His wife, Raeni added:

> Mhmm, you just have to be real careful, structure everything so that you make sure you're OK and you won't end up shootin’ yourself in the foot.

Amadeus and Raeni demonstrate an intricate knowledge of Amadeus' max earnings with his SSDI, but also as a contractor, he is able to earn money that does not contribute to his maximum wages. In this sense, Amadeus is not merely complicit within the system, he is an expert on working the system, an expert status that applies to his wife as well, who understands the intricacies of their finances, because she receives state funds to be Amadeus' caretaker. While the content of Amadeus' explanation demonstrates his agency in the navigation of SSA regulations, his syntax comes through to evidence the double-bind situations he has faced. For instance, when he refers to his earlier time working at the radio station, he uses the passive verb construction: "it kind of put me in a situation where I almost lost all my benefits." This passive grammatical construction emphasizes the possibility of losing his moral and economic agency. In contrast, both he and Raeni use active verbal constructions to refer to how they successfully navigated the regulations: "*I decided* to be an independent contractor;" "*I try* to always make sure," *"you* just *have to* be real careful." These constructions position Amadeus as a grammatical, moral, and pragmatic agent - a person in control of his financial wellbeing.

Additionally, I heard many stories of loopholes or workarounds that people found in order not to jeopardize their benefits. Most commonly, life-partners who received SSI and SSDI would choose not to marry each other, as their combined incomes would put them over the edge of earnings for a couple. In this sense, they created unique "crip" kinship structures (Kafer 2019 Rapp and Ginsburg 2001; 2011) by forming coupleships, even though these arrangements were not recognized by the state. I also spoke with some people who managed even more precarious situations. For instance, one disabled interlocutor was a Mexican immigrant. He was eligible to work under the Deferred Action for Childhood Arrivals (DACA) program, an Obama Era policy that allows some undocumented immigrants who were brought to the country as children to receive a two-year renewable period of deferred deportation and a U.S. work permit (University of California at Berkeley 2019). While he had a somewhat protected status in the country, his wife was an undocumented immigrant. His wife was his caretaker. If she had had a work permit, she would have been eligible to receive state funding for providing his care. As she was undocumented, they had to find a way to secure this money in their precarious situation. So, they had his sister, who had been granted U.S. citizenship pose as his caretaker for the state. She would transfer the money she received over to my interlocutor's wife so the couple could have some income for the wife's care-taking labor. These examples of loopholes or workarounds might, on the surface, appear to be examples of agency in the form of resistance; however, none of the narrators cast themselves as able to completely resist the strictures of SSA regulations. Rather, they manage to be complicit within the strictures and the loopholes they allow. This complicit agency enables them to construct a life around a limited income that is livable, though never enough to provide a life without financial worry.

I am not suggesting that all disabled people exercise complicit agency. This study population is more likely to experience a compounded disfavored intersection of ethnic-racial minority and disability status and economic disenfranchisement. It is no coincidence that just over 50% of Rancho's SCI patients are eligible for public insurance and nearly all of those I interviewed - those who returned to the hospital as community members or as peer mentor employees - relied on some form of assistance from SSA. Of all Rancho's patients, it tended to be those who were marginalized who found their way back to the hospital and who found the opportunities, like work opportunities as peer mentors, most appealing. Indeed, many of the peer mentors discussed the benefits of their job, which gave them flexibility with hours that do not jeopardize their SSA benefits.

One of the ways that KnowBarriers accomplishes this compromise is through offering employment on a contract basis. This form of employment, which has grown increasingly common in the “gig economy” (Gray and Suri 2019), provides no protections for employees, as contract workers are not eligible for benefits such as health insurance. Furthermore, to become a peer mentor with KnowBarriers, employees must first volunteer for six months. The forced volunteerism and the contract work place these marginalized workers into precarious work situations. Yet, none of the employees I interviewed critiqued their work as contractors. Rather, they expressed a sense of gratitude for their flexibility, especially as it relates to SSA restrictions.

While these labor practices may appear to be exploitative, the employees appreciated that their jobs allowed for a flexibility that is highly beneficial for living with a disability and depending on SSA benefits. As such, the safety net that exists to provide economic support for disabled Americans incentivizes not working. This constraint, along with the limits of performing labor with a disabled bodymind, figure many disabled people into a position in which they learn to live with the resources that they are provided, however limiting they are, and to not go over their restrictions. The gratitude that peer mentors express for their flexible work is a form of complicit agency within the neoliberal confines of contract work. This complicity is the result of ambivalence between options that have benefits and drawbacks. Disabled people who receive benefits must weigh many factors as they navigate their ability to earn money, keep their bodyminds healthy, and ensure that they have access to health insurance. As they negotiate these structural limitations, they exercise complicit agency amidst a sea of conflicting choices. In the next section, I explore the way in which interlocutors weave a sense of value against the backdrop of American ideological values of productivity and rehabilitation’s emphasis on able-bodyminds.

Ideological constraints and constructing value

While having the ability to earn money is valuable to many disabled people who receive SSI or SSDI, all those whom I interviewed saw their time at Rancho as providing alternative values. For those who worked, like peer mentors, the wage was generally secondary to the moral dimension that they saw in their work. Dale, a volunteer peer mentor, noted, “The wage is the feeling of giving back... I get out of it some feeling inside that money can’t buy.” While scholars have discussed the ways that exclusion from labor is an iteration of the lack of social value of disability (e.g. Mitchell and Snyder 2015; Stone 1985), disabled people are likely to create their own sense of value in their engagements. Through this identity work disabled people corporeally and discursively construe their activities within a meaningful life trajectory. I argue that this moral endeavor is a form of complicit agency within institutional and state constraints and affordances. Dale sees his work as having positive value. His self-representation is not a critique of the structures through which he, a poor disabled black man, ended up volunteering, unable to even earn a wage for his time.

In addition to the concrete constraints that disabled people need to navigate, there are several ideological constraints that suggest disabled bodyminds position them as less valuable beings. negatively impact the psyche of disabled people, especially in the face of stigma (see Black 2012; Phelan et al. 2008; Shuttleworth and Kasnitz 2004). In the tradition of interactional sociology, from Simmel (1950) to Goffman (1956; 1963), encounters between normative group members and marginalized ‘others’ are a means through which stigma is lodged, and distinctions between people who are marked (atypical) and unmarked (normative) are reified. These distinctions have been elaborated in the work of Ochs (2015), Engelke (2013) and Garland-Thomson (2009), who examine the contours of interactions with disabled people to demonstrate how stigma becomes a lived reality. The focus on daily interaction evidences that disabled people encounter stigma on a routine basis. Stigma is one of many constraints that they must navigate continually.

Another ideological constraint operates in the rehabilitative setting of Rancho itself. Rehabilitation is a field within bio-medicine, which demands active compliance from patients undergoing care. Patients are expected to put in effort following an injury to ideally return to the life and ability that they possessed before the injury. If they cannot return, it is expected that they strive to achieve the most able-bodymind that they can attain. If patients refuse to participate in the activities demanded by clinicians, they may be kicked out of the hospital to make room for people who "want to be there" (a phrase I heard repeated throughout my fieldwork). We can think of these constraints as moral imperatives or Aristotelian virtues that tied to sedimented practices that need to be mastered to be recognized as having good character (Laidlaw 2014, MacIntyre 1981). There is Aristotelian virtue in active participation in rehabilitation: a patient is viewed as virtuous for participating fully in his or her "return" to a full life. According to this moral framework, disability is a lack to be overcome through grit and determination. Yet, disabled people who cannot function independently reveal the cracks in the underlying values of agency and productivity (e.g. Friedner 2015; Nussbaum 2001). Accordingly, many of the disabled people whom I met over the course of fieldwork had their own versions of virtues related to productivity. I extend the definition of virtuous productivity to include not simply working to earn financial capital but also to encompass the sense of virtue that many interlocutors evinced: they were productive in *doing something good* with their lives.

Focusing specifically on deaf employees in the neoliberal economy in India, Friedner (2015) notes that disabled employees find a sense of *value* in social relationships with each other

– a kind of “moral economy” (Friedner 2015, 78; see also Mattingly 1998; 2010; 2014a on weaving hope into uncertain futures for disabled people). Value is a moral and economic sense of one’s worth, in a lifeworld in which disability invites stigma. In this section I shed light on how disabled people describe ‘alternative forms of value’ (Friedner 2015).

Ed embodied this sense of alternative value through his narrative of his time at Rancho. He came to enjoy spending time at Rancho a year or so after his spinal cord injury. Though he initially hated rehabilitation and was an “uncooperative” patient, because he refused to do his prescribed physical and occupational therapies, he explained that as he came to grips with the new realities of his life and disabled bodymind, his attitudes shifted. His account walks through the oppressive ideological values of disability (and blackness) that he had appropriated by wanting to prove his productivity and ability in a normative sense. Ed told me that he used to come to Rancho to “decompress.” I asked him how he ‘decompressed’ at Rancho and he explained:

> “Just (being) here. (.) Actually, there’s more of a normalcy here… Out there it’s like, “Oh you don’t quite fit in. You don’t quite fit in.” And they look at you like “Oh you don’t quite fit in. You’re using a WHEELchair.”

Ed shifts his footing as he switches between his own voice and the voice of some imagined other who repeats “You don’t quite fit in.” In the voice used in this reported speech, Ed imagines the inner dialogue of likely able-bodyminded people. Such harsh imagined stances help to explain his feelings about Rancho, where he could “decompress.” He links this need to decompress also to his attendance at a university where he got his teaching degree. He explained that as the only black student and wheelchair user in his classes, he had the sense that “You’re looked at different. You’re treated different. And you have to work even harder.” In this poignant description of his sense of social expectations, Ed alludes to the stigma of disability and blackness as categories that figure him outside of the productive norm. As noted earlier, he felt strongly the need to overcome these expectations and went on to complete his degree, eventually working as a teacher in a special education classroom. Furthermore, in his account he uses the generic second person pronoun to make his explanation more general, perhaps as a way of creating distance between that past self, the one who felt the need to disprove social expectations, and his present self that no longer teaches, to preserve his bodymind. Ed's movement between multiple past and present selves demonstrates the moral conflict between the constraining virtues surrounding disability and his struggle to weave a 'hopeful' life (Mattingly 2010).

While Ed's past self was invested in the neoliberal values of proving worth through salaried productivity, the impaired self with which he came to grips had different values: values of his own productive construction. Ed, and most of the disabled people whom I met during fieldwork, had distinct moral valuations of *productivity* - doing something with their lives - which both reflected and subverted virtues surrounding labor. Ed works within dominant societal virtues that position him as non-agentive. Ed found ways to be what he considers a productive, virtuous member of his community. He attached moral character to his ability to impact change. Ed told me:

> "I ah- I like to do (1.3) whatever it takes to (.) invest into RANCHO becoming (.) a- a better (1.5) environment (.) for-for helping patients. (.) Yeah. I have PURPOSE with that."

Ed's language throughout this utterance is marked with dysfluency. He pauses often and restarts statements several times. The dysfluency does not convey a speaker lacking in confidence in the content of his declarations. Rather, it suggests that he is carefully weighing his words. The affective weight of these words is delivered with the last sentence, “I have PURPOSE (spoken more loudly than the other words for emphasis) with that.” The verbs in this statement indicate that Ed is acting agentively; with verbs like “invest,” “become,” and “help” he presents himself as someone who is in control of his actions. What is significant is that the predicated actions and states are directed towards transforming Rancho as an institution and, indirectly, the patients at Rancho. Ed constructs virtue for himself within a projected vision of what Rancho potentially can become for patients.

The idea being a part of a community and having a sense of achievement was a theme commonly repeated by Rancho peer mentors and others. DB, the African American paraplegic who would roll around campus in his power wheelchair with a speaker in the headrest, explained how important it was for him to be on campus to feel like he had accomplished something:

> I- I love this place because (.)there's a lot of- PEOPLE that you see here, (.) they're positive. You know, they're- they haven't given up. They're still pushing forward, you know, and I love that that that spirit.

Although DB told me that he was not eligible to work as a peer mentor because of a history with incarceration, he thought of himself as an informal peer mentor. He clarified this by saying. “I don’t volunteer, but I HELP people.” He would spend his time on campus working out, attending doctors’ appointments, and chatting with folks whom he thought might benefit from his lived experience. He felt the need to spend time at Rancho all the more important, because his life partner would “drain his energy” with what he described as negativity. She was living at a nursing home because multiple strokes had left her unable to care for herself. Ironically, DB felt that being at Rancho, where he was surrounded by disability, was a more meaningful use of his time than being with his newly disabled partner, who could not seem to pull herself out of depression. Perhaps it was the sense of productivity and meaning that DB was able to craft for himself as well as the ethos of productive community that made Rancho such a preferred, virtuous escape for him.

Having purpose for Ed involved throwing himself into volunteering at Rancho. For the thirty-nine years following his injury, he has continued to visit the hospital, not just for medical appointments or for the sense of normalcy, but for the opportunities of involvement. Rancho became a place where he can conceptualize his life as one in which he contributes to a community. Over the years, he became involved as a participant and coach of wheelchair sports programs there. He would also be assigned to visit patients. As someone who has multiple temporal selves, he could have compassion for people coming to grips with their disabilities because of his past experiences. Simultaneously, he could provide a glimpse of the patients' future self.

Eventually, a recreational therapist showed him an artistic technique called marbling, the process of creating an art from mixing oil pants on top of a water base, and then laying objects, like paper on top of that design to transfer to art from the water base to the object (see Figure 5.4). Along with the rec therapist, he started a marbling program for inpatients, outpatients, and the many visitors to the hospital who would benefit from the process of working with their hands on an artistic project, a project that he currently oversees and is in the process of training others to take over.

Figure 5.4: Ed's protégé marbles. The black and white photograph depicts a woman with a large bun atop her head and a Rancho volunteer apron. She is pouring water from a watering can onto a board in a tub. This is part of the process of marbling. Photo by author.

Figure 5.5: Drying pieces of marbling art. The color image shows a close-up of one piece of marbling art on a paper left to dry on a rack. The artwork is red and blue paint swirling together. Photo by author.

Figure 5.6: Drying pieces of marbling art, side-view. The color image shows the rack on which pieces of marbling art are drying. The rack is plastic tubing reinforced by wooden sides. It is speckled with paint from previous pieces of art that have dried on it. Photo by author.

Within the conditions that limit his productivity (like SSI limitations on work and the physical conditions of work), Ed has crafted moral attachments to his unique form of productivity. In this vein, Ed demonstrates action and agency. He keeps himself engaged, an important condition of living his virtuous life. Ed did not reflect on his life in terms of passivity or stagnation. The antithesis of agency - doing nothing and relinquishing his activities and care to a skilled nursing facility - is what he and others fought against in the 2003 lawsuit. As a contrast to his experiences of 'doing something,' Ed told me about his friend, Jim who had fallen into a life of inactivity:

> My buddy Jim, the T12 para, he lost- he's losing function in his arms. He can hardly move it <referring to his manual wheelchair>. And so he's in bed with a pressure area… We had set it up, to get in when Dr. Patel, (he) would fix his behind. "What you doin?" And he got issues with hospitalization and doctors and I suggested the power chair and he CURSED me out… Now he's literally bed ridden. °"Jim what you doin"° And he don't even get out of bed until 2 or 3. Like "Jim what you doin?" He said "I just can't get up" . . .But ah, yeah he (cussed) me out about the power chair. Well, I zip over there <in a power chair> on the bus and train, first time experiencing it, roll up in his house and I'm like "man what you doing?" Still up in bed ..."I'm tired of pulling this ten pounds of weight with me."

Ed recounts difficulty in trying to get his friend, Jim, not to fall into a life of inactivity; however, this is a difficult feat, which Ed narratively constructs himself failing. He describes the deterioration of his friend's bodymind: he cannot seem to get himself out of bed anymore. Jim refuses to switch from a manual wheelchair to a power chair, a choice that Ed himself made reluctantly but that ultimately gave him ‘mobility’ and ‘freedom.’ He weaves in and out of his past voice and present voice throughout the narrative. This lamination of voices (Hill 1995) is a means through which Ed shifts moral footing throughout the narrative. He moves in and out of description of the present context, such as “My buddy Jim… [is] losing function in his arms,” to recount the past, like “I suggested the power chair and he cursed me out.” In the constructed voice (Hill 1995; Tannen 1989), he seems to quote his past self, “Jim, what you doin?” This echo of the past voice does not follow a linear temporal framing (Bruner 2002, Ochs and Capps 2001; Rymes 1995), Rather, it serves as a rhetorical trope through which Ed begins to fuse the affect of his past and present self: a self that cannot understand Jim’s reluctance to take better care of himself. Ed builds a contrast between his agentive self (both past and present) and Jim’s non-agentive, deteriorating self.

Some of Ed’s lexical choices further enhance the agency with which he constructs himself. He uses lexical terms that imbue his movement with intense actions - he *zipped* over to Jim’s house on the seemingly winding path of bus and train, *rolled* through the door, only to find Jim still in bed. This dynamism contrasts starkly with his description of Jim’s ten pounds of (heavy, stagnant, passive, unproductive) weight. Though Ed implores Jim, “Jim, don’t give up on me,” he could not seem to reach his friend who, through his inactivity, transitioned from a partner in action to dead weight, according to Ed’s framework of virtuous productivity. He contrasted his daily rhythmic cycle with Jim’s to allude to Jim’s ‘unhealthy’ bodymind:

> I literally have to get in bed at 4 or 5 in the afternoon, he just getting up at 3.
>
> “Jim, what you doin?” I do get up at 6 though. I enjoy that, early morning hours.

What was Jim doing? This question poetically circulates in Ed’s narrative as a refrain for both of us, maybe for all of us. What you doin Jim? I imagine that Ed’s response to that rhetorical question was - nothing. In Ed's virtue framework, Jim was doing nothing. Jim's inactivity is construed as part of a slow death (Berlant 2007; Puar 2017). Jim did not leave the house. He did not have daily activities to which he formed meaningful connections. The health of his bodymind was falling apart. Ed's explanation of Jim highlights the inverse of Ed's virtuous agency: complete passivity and wasting away in bed. With his recurring lamentative question, "Jim, what you doin?" Ed positions agency within Jim's grasp. He constructs it as an agency that Jim just refuses to will himself to realize Ultimately, the fight against ending up in thick stagnation, wasting away in a nursing home or bed, is what fueled passionate patient protests and legal action during the near shutdown of Rancho in the early 2000's.

Through Ed's accounts of his work history, the limitations imposed on him, and Jim's stagnation, Ed presents himself as an active person caught between polar potentialities: on one end of the pole, a productive able-bodyminded member of society in the normative sense of working for hours and hours; and, at the other end, a disabled person lying in bed, dying a slow death from a health condition. Ed's virtue in what he 'does' exists along this pole, betwixt and between normative notions of agency and passivity. While Ed's life is precarious (he cannot work too much because of the limits of his bodymind and SSA, he resists doing nothing because, to do so, would be do die without virtue). Ed constructs his virtuous self through narratives that foreground his competence and efficacy on behalf of others (cf. Capps and Ochs 1995; Garro and Yarris 2009; Mattingly 1998; 2010; 2014a). In this life he 'does something,' though this 'something' strays from normative assumptions. Ed does not resist the neoliberal framing of productivity; instead, he is complicit within it and forms his own interpretation to acknowledge and generate his life.

Conclusion

Returning to the question of what rights the legal action in the early 2000’s protected, it appears that the right to complicit agency is one artifact. This outcome contrasts with my expectations at the start of fieldwork, when I thought that I would encounter disabled people who were politically motivated to ameliorate the structures of their oppression. What I found instead was people making their way through their lives with limited resources and the ability to stretch themselves only as far as they could while still maintaining their mental stability. Importantly, in narratives and other embodied communication, they portrayed themselves stances as agentive.

One of the last events that I attended during fieldwork was the 3rd Annual L.A. Disability Pride Parade & Festival on October 7, 2018 in East L.A., not far from Downey. I was invited by Rancho community members who I routinely encountered. During the festival, hosted by the Southern California Resource Services for Independent Living and Hilda Solis, from the L.A. County Board of Supervisors, I realized that my expectations of politically awakened, electrified, and agentive disabled people, angry at their circumstances and joining through community was, again, incorrect. Instead, the event was rather mild. I walked around the event booths at which different organizations had set out fliers: some nonprofits; some community groups; some medical supplies companies; and some religious groups, among others. The parade, led by a high school color guard squad, began around 10 a.m. As we marched out of the event staging area and into the open street, we were basked in warm sunlight. The crowd, which was about 100 people large, quickly thinned out, as people quietly pushed and walked at their own paces. I had expected chants demanding “Nothing about us without us!” I looked for signs calling for fair wages for disabled employees. Instead, we marched together as a docile crowd. Those who tried to enliven the crowd with chants such as, “We’re here, we’re loud, disabled and proud,” were met with silence. When a chant did catch on, it would quickly grow more and more muted into oblivion.

As I stared around at the crowd, many of whom resembled the population that I was accustomed to at Rancho, I wondered if I was observing a real-life example of Puar's (2017) critique of the Disability Rights Movement. For Puar, collective action for disabled people has been exercised only from a place of privilege. While collective action at Rancho helped to keep the institution open, it was not a priority for the folks who had their needs met after the protests and legal action in 2002 and 2003. What I was witnessing was the complicit agency that disabled people exercised to navigate their social worlds; representing themselves, their decisions, and life commitments as valuable. It was the inverse of protests in which disabled folks display their bodies as a sign of frustration with debilitating systems of capitalism (Açıksöz 2020b) Instead, the collective of marchers and those at Rancho displayed embodied performances of capability.

Figure 5.7: Two friends at the Disability Pride Festival. The photo shows the backs of two people, sitting only inches apart from each other. One of the friends has short hair and a high-backed wheelchair. The other has a lower back on her wheelchair. Her long hair spills over her shoulders. Her wheelchair has a metal sign reading "Raider Nation." In front of the friends a crowd prepares for a speech. Photo by author.

Figure 5.8: Cousins at the Disability Pride Festival. The color photograph shows two young, smiling children on scooters. They each carry handmade signs, written on neon green paper. One sign read "I love my cousins the way they are Mark & Marcus." It is adorned by the international wheelchair icon and hearts. The other sign reads "Love knows no boundaries." Photo by author.

Figure 5.9: A family marches in the Disability Pride Parade. In the center of the color photograph, a man sits in a yellow wheelchair. He rests his head on the headrest and his head is softly touched by an older woman. Behind the man in the wheelchair is an older man with a sign reading "Born to stand out." Photo by author.

In this chapter, I have explored the moral and pragmatic constraints through which disabled people with intersecting economic disadvantage and ethnic minority status must make their way. Impairment often imposes exclusion from the labor market for disabled people, many of whom work limited hours and depend on public assistance. Furthermore, disability is associated with stigma and the sense that a disabled life is a less valuable life. Despite adversity, many members of Rancho's disability community construct virtue through agency on their terms leading productive lives. This version of virtuous productivity is not inscribed in more conservative bio-medical or neoliberal approaches to rehabilitation. Attaining value is a source of tension between the constraining forces in the lives of disabled people - such as SSA regulations on earnings, the physical capability to work, and stigma - and the agentive, creative means through which they weave their lives into frames of worth. Complicit agency is a means of working within structures of disenfranchisement; the underlying ambivalence is made obvious through the moral footing disabled folks take, as they recount their experiences.

While disability studies scholars have critiqued notions of agency as they are presented in the narratives of disabled people (e.g. Rembis 2013; Wolfe 2014), such criticisms have not accounted for the possibility that these narratives are simply a practice of weaving a thread of hope into an uncertain future, particularly for less privileged disabled people. This chapter has proposed complicit agency as a means of coping with the intricacies of structural constraints and affordances. Disability studies can profit from this concept, which nuances the agency with which disabled people construe their lives.

CONCLUSION

In this dissertation, I have set out to depict the community, institutional, and interactional processes through which disability is produced and inscribed. I have documented across historical, ethnographic, quantitative and discursive approaches. These analytic shifts have allowed me to slip between the micro and macro contexts through which disability comes to be a lived experience. Focusing on the affective stances communicated among disabled interlocutors, I have demonstrated that "doing" disability is a continual process of alignment and disalignment with people, impairments, moralities, and constraints of the political economy. In examining Rancho's past, I have argued that the historical context of the poor farm created a space in which disability has 'belonged' throughout the institution's lifespan; disability brought (and brings) together a community; disability was (and is) a medical category to be diminished and cured. Within this institutional framework, disabled people are interpellated into a rich social world, for better or for worse. In the introduction, I recounted a peer mentor staff meeting in which a doctor was unable to remove himself from the doctor-patient participant framework, thus interpellating the peer mentoring staff as perpetual patients. Just as poor farmers were once viewed as the objects of charity and healing, the disabled people who today come to regard the institution as a community are read as the objects of philanthropy. Often, they "respond… as such" (Carr 2009, 317).

In Chapter 2, I outlined the history of Rancho to draw a temporal connection between its past as a poor farm and its present as a public institution where disability community (as well as undesirable attitudes towards disability, like paternalism) thrive. I read Rancho's history from the perspective of biopower (Foucault 1990). This approach differs from previous historical accounts, which emphasize Rancho's philanthropy and ability to 'help those in need' (Fliedner 1990). What such histories have left out and what the lens of biopower reveals is that the poor farm and later rehabilitative approach to impairment has created the very condition that it sought to relieve or cure. Rancho has existed as a zone of exclusion (Agamben 1998; Biehl 2005) since the drive for “population control” arose with waves of immigrants into Southern California. According to this historical perspective, Rancho’s history is carceral, a means of state control of unruly populations. I drew a temporal thread between the poor farmers, whose labor was viewed as a charitable gift, and the peer mentors, who have internalized the sense of philanthropy and express gratitude that they are able to work, even when they are not paid for their labor.

Chapter 3 laid out the theoretical premise of thick sociality, the dense networks of relationships among disabled folks at Rancho. I argued that, within this milieu, people are socialized into a disability habitus, a set of dynamic dispositions with which people operate as they navigate world in which impairment is ever present. This chapter offered an interdisciplinary theory of community, combing approaches from rehabilitation, anthropology, and sociolinguistics. Through this multi-dimensional approach, I demonstrated that a rich community exists at the institution, and there is evidence for its pervasive influence in everyday conversations.

In Chapter 4, I highlighted everyday conversations in the hospital by examining interactions during peer mentor training sessions and SCI starting out classes. I argued that these conversations offered moments of socialization during which newly injured patients cultivated their disability habitus. Key features of conversational encounters include properly identifying oneself and one’s injury, openly discussing topics that might be taboo in another context, and orienting to a future impaired self with an ordinary life. In these conversations, disability expertise afforded possibilities for learning. As discussed in the next chapter, the value of peer expertise is mediated by social contexts that perpetually disenfranchise disabled people.

Chapter 5 addressed the question of agency among Rancho community members, many of whom experienced intersections of marginal identities. Examining the interplay of agency, virtue, and value, I proposed the concept of complicit agency to describe the ways people did not resist the ableist structures into which they were embedded but worked subversively within them. Through complicity within the confining regulations of social security, disabled people positioned themselves as virtuous actors and imbued their discourse about their time at Rancho with a sense of value. The main point of the chapter was not to assess the degree of agency that interlocutors demonstrated, rather it was to highlight the ethical struggles in which people are enmeshed and the communicative strategies that configure conflicted, time-tempered selves across paradigms of virtuous productivity.

Although the focus of this dissertation has been on Rancho Los Amigos, the findings apply beyond the context of its hospital. The historical transformation that took place from poor farm to peer mentors is an artifact of larger social and political shifts with regard to impairment. Rancho happens to exist as a space that generates this continuous history and the changes, or lack thereof, that have transpired.

Theoretically, this analysis has demonstrated the affordances of attending to the minute contours of daily interactions in order to draw conclusions about the movements and impacts of macro social structures. This interactionally-focused approach builds a layer of complexity into disability studies, a field largely centered in humanities. Describing the life-worlds of everyday disabled folks compliments the research in disability studies, in which media, literature and art analysis have been tools for imaging better, more compassionate, empathetic and enriched crip futures. However, only through deep person-centric analysis can we understand the muddy waters through which disabled folks swim on a moment-by-moment basis. This approach hopefully inspires empathy and understanding for the disabled folks who do not always reach toward the utopian vision imagined in disability studies. Through illuminating the nuances of small moments, it becomes possible to grasp the immense creativity and generativity nourished by disability community, even those communities for whom complicity within ableist and oppressive structures is a form of agency and resilience.

Suggestions for rehabilitation

If this dissertation provides any direct implications for the field of rehabilitation, it is that peer mentoring programs have transformative potential through their ability to introduce people with impairments to a disability community. In doing so, they introduce disabled people to a network of resources and knowledge to which they are unlikely to be exposed through interaction with their (mostly able-bodyminded) rehabilitation clinicians. Hospitals and institutions should heed the advice of the World Health Organization to instill more peer mentoring programs (World Health Organization 2011; 2013). They should, however, differ from the World Health Organization's understanding of peer mentoring as a way to "reduce health care costs" (World Health Organization 2011, 12). This dissertation has demonstrated that the bodies of knowledge that disabled people possess, only attainable through lived experience, is rich and deep. It has also demonstrated that disabled people are far more likely than able-bodyminded people to be economically disenfranchised. At Rancho it was typically those who experienced intersecting dimensions of marginalization who were drawn back to the hospital to become peer mentors. Rehabilitation facilities need to recognize the importance of peer mentoring and value the knowledge that is disseminated through them. While that knowledge may not have been acquired through formal schooling, it likely took as long, if not longer, for many as a degree in the medical field.

Suggestions for future research

The research presented in this dissertation has built upon the growing cannon of disability anthropology (see, for example, Ablon 1981; Açıksöz 2012; 2020a; 2020b; Bloom 2019a; 2019b; Davis and Boellstorff 2016; Erevelles 2011; Friedner 2015; Ginsburg and Rapp 2013; Hartblay 2017; 2019; Ingstad and Whyte 1995; 2007; Kasnitz and Shuttleworth 2001; Kohrman 1999; 2003; 2005; Murphy 2001; Nakamura 2006; 2013; Phillips 2010; Shuttleworth and Kasnitz 2004; Wool 2015), a field which de-naturalizes impairment as a taken for granted biological category and, instead, attends to the social contexts and relationships through which disability is enacted. The field is inherently interdisciplinary, combining approaches from disability studies, cultural anthropology, medical anthropology, and, in this dissertation, linguistic anthropology. I suggest that future research continue to draw from these conceptualizations of impairment in order to interrogate models of disability, such as the curative model (Clare 2017), which have imposed harm on disabled bodyminds through circulating ideologies about disability as something to be contained and done away with. This step is necessary to move towards a crip futurity (Kafer 2013) in which our imaginations of the future include disability, rather than a world in which disability has disappeared. In such a "disability world" (Ginsburg and Rapp 2013), impairment can be recognized as a source of rich social life, like the creative social world at Rancho, illuminated in this dissertation. At the conclusion of this dissertation, I realize that my analysis has revealed more questions than it has answered for me. The disability community that I have endeavored to understand is far more complex than I have analyzed here. The dissertation draws from a wider archive of observations and interviews that I conducted during fieldwork. Even this selection of data leaves many questions that were beyond the scope of this dissertation. Some of the potential queries that warrant further examination are: What is the interplay of gender and disability in the rehabilitative context?

While gender performances were undoubtedly an aspect of the disability habitus among my largely male interlocutors, an adequate analysis fell outside of the scope of inquiry. How does this disability community in a rehabilitation institution differ from other, grass-roots disability communities? How do people with non-apparent impairments integrate into communities that circulate around disability?

I continue to grapple with the difficulty of conducting research on such an expansive category as disability. Centering my research around spinal cord injury rehabilitation made logistical sense at the start of the project because of Rancho's renown in this area and because of close personal connections I have to people with SCIs. Additionally, the research process of grant proposals and funding lends itself to imagining impairment as something that fits neatly into sperate boxes. However, I found it difficult to separate out spinal cord injury from the ever-unfolding label of disability, which, when applied, brings many people together. Many interlocutors had multiple impairments and disabled folks typically did not structures social networks around type of impairment. This complicated my attempt to understand the nuances of spinal cord injury rehabilitation. In future projects, I intend to lean into these complications and explore disability as broadly as possible. I suggest that future research not simply address, but embrace the messiness of disability. This will require pushing back against funding requirements that want researchers to envision cleanly outlined projects. It will require a degree of comfort in an ambivalent space of unknowing. Only then can the categories that govern knowledge production be broken enough for growth.

Epilogue: Disabled voices in crip futurity

I turned the first draft of my dissertation draft in on March 16, 2020, the same day that the Bay Area announced the ‘shelter in place’ orders to prevent the spread of Coronavirus (COVID-19). This was the first of such orders limiting access to public spaces and businesses in the United States. Shelter in place orders or similar directives would soon sweep the country as COVID-19 spread. This imposition, which still limits movement in public places as I write, has given the general population a sample of the imposed slowness, limitation and boundaries to which many disabled and ill folks are accustomed. The forced quarantine has been a small taste of the binding institutionalization discussed in this dissertation. Yet, even during this pandemic, vulnerable people face especially difficult situations. For instance, the peer mentors who usually depend on income from their work have moved to online peer mentoring and are facing severely reduced hours. Many folks have also expressed concern over the eugenic logic that is now being openly discussed in discourse on rationing medical supplies and weighing the importance of a strong economy against the potential death of people at high risk to COVID-19. Despite the strain of the virus on marginalized people, I was not surprised to see that grassroots organizing in disability communities quickly began to take shape to form networks of resources for sick and disabled people in need. Disabled poets and artists took to Zoom to share their creativity and inspiration with crip comrades. The day after I turn in this dissertation in, I will attend an online crip dance party. Even in these unprecedented and trying circumstances, the generativity of disabled communities cannot be stifled. Crips have leaned into their ability to build communal solidarity, which has been a truly life-saving practice for so many.

The Disability Rights Movement has emphasized the necessity of involving disabled folks in the future we build. This is reflected in the slogan: “Nothing about us without us!” Yet as this dissertation and recent critiques of disability studies and disability rights reveal, the diversity of those voices needs to expand. The slogan, too, needs an update because “nothing about us without us” is too limited in its imagination. The first-person pronoun “us” - people with impairments - might be better imagined more specifically, yet less limiting so that it would read “Nothing about the future without us!” As crip futurity unfolds, we must attend to the voices of those who enact the process of disability: they represent a largely untapped well of knowledge, creativity, and resilience that shed crucial light and meaning on our social worlds.

APPENDIX 1

Ethnographic methods*

Method	Description	Data
Participant observation	Observed everyday life in different settings.	Field notes; audio recordings; pictures
Focal person follows	Shadowed key informants during their work or activities throughout a day.	Field notes; audio recordings; pictures
Semi-structured interviews	Conducted interviews (between 30 – 120 min.) with participants about their experiences with disability and rehabilitation. Interviews followed an outline, but structure was open and conversational.	Field notes; audio recordings
Adapted Community Integration Measure	Survey instrument administered to participants, designed to measure perceptions of Rancho as a community.	Quantitative data (survey results)
Disability phenomenology	Reflected on experience as a disabled person, my position within the institution, and my relationship to interlocutors.	Field notes

**Unless otherwise specified, data is qualitative.*

APPENDIX 2

Research settings

Setting	**Focus**	**Activity**
Inside Rancho	Inpatient-centric	SCI Starting Out Classes
		Mentor-patient visits
		OT/ PT appointments
		Events (e.g. outings, visit from non-profit groups)
	Outpatient-centric	SCI Support groups
		OT/ PT group appointments
		RT activities
		Working out at wellness center
		SCI Transition Clinic
		Events (e.g. quadriplegic meet-up)
	Peer mentor-centric	Peer mentor training
		Monthly staff meetings
		Events (e.g. peer mentor summer bbq)
	Hospital-wide	SCI Games
		Patient art shows
		Rancho weekly Farmer's Market
Outside Rancho	General events with presence of Rancho community members	Abilities Expo
		L.A. Disability Pride Festival

APPENDIX 3

COMMUNITY INTEGRATION MEASURE

For each of the following statements, please indicate whether you agree or disagree

1. I feel like part of this community, like I belong here.
☐ Always agree ☐ Sometimes agree ☐ Neutral ☐ Sometimes disagree ☐ Always disagree

2. I know my way around this community.
☐ Always agree ☐ Sometimes agree ☐ Neutral ☐ Sometimes disagree ☐ Always disagree

3. I know the rules in this community and I can fit in with them.
☐ Always agree ☐ Sometimes agree ☐ Neutral ☐ Sometimes disagree ☐ Always disagree

4. I feel that I am accepted in this community.
☐ Always agree ☐ Sometimes agree ☐ Neutral ☐ Sometimes disagree ☐ Always disagree

5. I can be independent in this community.
☐ Always agree ☐ Sometimes agree ☐ Neutral ☐ Sometimes disagree ☐ Always disagree

6. I like where I'm living now.
☐ Always agree ☐ Sometimes agree ☐ Neutral ☐ Sometimes disagree ☐ Always disagree

7. There are people I feel close to in this community.
☐ Always agree ☐ Sometimes agree ☐ Neutral ☐ Sometimes disagree ☐ Always disagree

8. I know a number of people in this community well enough to say hello and have them say hello back. ☐ Always agree ☐ Sometimes agree ☐ Neutral ☐ Sometimes disagree ☐ Always disagree

9. There are things that I can do in this community for fun in my free time.
☐ Always agree ☐ Sometimes agree ☐ Neutral ☐ Sometimes disagree ☐ Always disagree

10. I have something to do in this community during that main part of my day that is useful and productive.
☐ Always agree ☐ Sometimes agree ☐ Neutral ☐ Sometimes disagree ☐ Always disagree

(from McColl et al. 2001)

APPENDIX 4

ADAPTED COMMUNITY INTEGRATION MEASURE

Instructions: For each of the following statements, please indicate whether you agree or disagree. Each time I say the word “community,” imagine Rancho.

1. I feel like part of this community, like I belong here.
☐ Always agree ☐ Sometimes agree ☐ Neutral ☐ Sometimes disagree ☐ Always disagree

2. I know my way around this community.
☐ Always agree ☐ Sometimes agree ☐ Neutral ☐ Sometimes disagree ☐ Always disagree

3. I feel that I am accepted in this community.
☐ Always agree ☐ Sometimes agree ☐ Neutral ☐ Sometimes disagree ☐ Always disagree

4. I can be independent in this community.
☐ Always agree ☐ Sometimes agree ☐ Neutral ☐ Sometimes disagree ☐ Always disagree

5. There are people I feel close to in this community.
☐ Always agree ☐ Sometimes agree ☐ Neutral ☐ Sometimes disagree ☐ Always disagree

6. I know a number of people in this community well enough to say hello and have them say hello back. ☐ Always agree ☐ Sometimes agree ☐ Neutral ☐ Sometimes disagree ☐ Always disagree

7. There are things that I can do in this community for fun in my free time.
☐ Always agree ☐ Sometimes agree ☐ Neutral ☐ Sometimes disagree ☐ Always disagree

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